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ABSTRACT

The transcript of the 1987 House of Representatives hearings on House Resolution 1871 concerning reauthorization of the federal Developmental Disabilities Program contains the text of the resolution, verbatim testimony and committee questions, prepared statements, and supplemental material. Organizations providing testimony or statements include the following: Department of Health and Human Services, American Psychological Association, United Cerebral Palsy Associations, Inc., American Association of University Affiliated Programs for Persons with Developmental Disabilities, National Association of Developmental Disability Councils, Office for Public Advocacy Division for Protection and Advocacy, and American Speech-Language-Hearing Association. (VW)

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ED295389

DEVELOPMENTAL DISABILITIES PROGRAM

HEARING

BEFORE THE

SUBCOMMITTEE ON
HEALTH AND THE ENVIRONMENT

OF THE

COMMITTEE ON
ENERGY AND COMMERCE
HOUSE OF REPRESENTATIVES

ONE HUNDREDTH CONGRESS

FIRST SESSION

ON

H.R. 1871

A BILL TO AMEND THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT TO EXTEND THE PROGRAMS ESTABLISHED IN SUCH ACT, AND FOR OTHER PURPOSES

APRIL 20, 1987

Serial No. 100-35

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DEVELOPMENTAL DISABILITIES PROGRAM

MONDAY, APRIL 20, 1987

HOUSE OF REPRESENTATIVES,
COMMITTEE ON ENERGY AND COMMERCE,
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT,
Washington, DC.

The subcommittee met, pursuant to notice, at 9:45 a.m., in room 2322, Rayburn House Office Building, Hon. Henry A. Waxman (chairman) presiding.

Mr. WAXMAN. The subcommittee will come to order.

This morning we will receive testimony on the reauthorization of the Developmental Disabilities program.

In 1987, approximately $84 million will be spent on Federal programs to assist States in providing necessary services to developmentally disabled persons.

Funding for this purpose is provided through four programs, including (1) formula grants to States; (2) grants to support protection and advocacy systems; (3) grants for special projects; and (4) grants to university-affiliated facilities.

With the enactment of Public Law 98-1074 in 1984, the statutory authority for the developmental disabilities program was strengthened. For the first time, a bill of rights for the developmentally disabled was set forth.

In adopting this important law, the Congress sought to assure that persons with developmental disabilities achieve their maximum potential through independence, productivity and integration into their communities.

The Developmental Disabilities program is vitally important to the millions of Americans with developmental disabilities. Its importance and success have made it enormously popular with the public, the Congress, and the administration.

I am pleased to note that Mr. Madigan, the Ranking Minority Member of the subcommittee, has introduced H.R. 1871, which extends the Developmental Disabilities Assistance and Bill of Rights Act for 3 fiscal years.

I understand that the legislation has the support of the administration.

The subcommittee looks forward to receiving testimony on this legislation as well as suggestions for other needed revisions in this important law from our witnesses.

Without objection, a copy of H.R. 1871 will be printed in the record at this point.

[The text of H.R. 1871 follows:]

I

100TH CONGRESS
1ST SESSION

H. R. 1871

To amend the Developmental Disabilities Assistance and Bill of Rights Act to extend the programs established in such Act, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MARCH 31, 1987

Mr. MADIGAN introduced the following bill; which was referred to the Committee on Energy and Commerce

---

A BILL

To amend the Developmental Disabilities Assistance and Bill of Rights Act to extend the programs established in such Act, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Developmental Disabilities Assistance Amendments of 1987".

SEC. 2. AUTHORIZATIONS OF APPROPRIATIONS.

The Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6000 et seq.) is amended—

(1) in section 130, by striking "$50,250,000" and all that follows and inserting "such sums as may be necessary for fiscal years 1988 through 1990.";

(2) in section 143, by striking "$13,750,000" and all that follows in the first sentence and inserting "such sums as may be necessary for fiscal years 1988 through 1990.";

(3) in section 154, by striking "$9,000,000" and all that follows and inserting "such sums as may be necessary for fiscal years 1988 through 1990."; and

(4) in section 163, by striking "$2,700,000" and all that follows and inserting "such sums as may be necessary for fiscal years 1988 through 1990.".

SEC. 3. ADDITION OF FAMILY SUPPORT SERVICES TO LIST OF PRIORITY SERVICES WITH RESPECT TO PERSONS WITH DEVELOPMENTAL DISABILITIES.

(a) IN GENERAL.—Section 102(11)(C) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6001(11)(C)) is amended—

(1) by striking "and";

(2) by striking the period and inserting a comma; and

(3) by adding at the end "and family support services.".

(b) DEFINITION OF FAMILY SUPPORT SERVICES.—Section 102(11) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6001(11)) is amended by adding at the end the following new subparagraph:

"(I) The term 'family support services' means services designed—

"(i) to strengthen the role of the family as the primary care-giver;

"(ii) to prevent out-of-home placement;

"(iii) to reunite families with family members who have been placed out of the home; and

"(iv) to maintain family unity.".

SEC. 4. REVISION OF DEFINITION OF SUPPORTED EMPLOYMENT OF PERSONS WITH DEVELOPMENTAL DISABILITIES.

Section 102(11)(F) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6001(11)(F)) is amended—

(1) by striking "paid" the first place it appears and inserting "competitive"; and

(2) by amending clause (i) to read as follows:

"(i) is for persons—

"(I) with developmental disabilities who are members of groups for which competitive employment has not historically occurred, or

"(II) for whom competitive employment has been interrupted or intermittent because of a developmental disability,

"who, because of their disabilities, need intensive ongoing support to perform in a work setting;".

SEC. 5. REVISION IN CATEGORIES OF REPRESENTATIVES ON STATE PLANNING COUNCIL.

Section 124(a)(3)(B)(ii) of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6024(a)(3)(B)(ii)) is amended by inserting "or previously institutionalized" after "institutionalized".

SEC. 6. EFFECTIVE DATE.

The amendments made by this Act shall take effect October 1, 1987.

○

Mr. WAXMAN. Our first witness this morning is Jean Elder, Acting Assistant Secretary for the Office of Human Development Services for the Department of Health and Human Services.

Dr. Elder, we are pleased to welcome you to the subcommittee. Without objection, your statement will be made part of the record.

STATEMENT OF JEAN K. ELDER, ASSISTANT SECRETARY FOR HUMAN DEVELOPMENT SERVICES-DESIGNATE, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY ROBERT E. STOVENOUR, ACTING COMMISSIONER FOR THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES

Ms. ELDER. Sitting with me, Mr. Chairman, is Mr. Robert Stovenour, the Acting Commissioner for the Administration on Developmental Disabilities.

I welcome the opportunity to appear before this distinguished subcommittee to discuss the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act.

Mr. Chairman, we strongly support the administration's reauthorization legislation which has been introduced by Congressman Madigan. This bill, H.R. 1871, reauthorizes the Developmental Disabilities Assistance and Bill of Rights Act for 3 years.

We are honored to have Mr. Madigan, the Ranking Member of this subcommittee, and a leader in the effort to provide strong support and services to the developmental disabilities population, as the sponsor of our legislation.

We want to thank Congressman Madigan and all members of this subcommittee for the support given to the Developmental Disabilities program and the genuine concern shown for our citizens who are developmentally disabled.

When Congress set out to help developmentally disabled people, it was providing for one of the most vulnerable groups in the Nation. An individual is considered developmentally disabled when severe, chronic disabilities attributed to mental or physical impairments are manifest before age 22.

Such disabilities must cause substantial limitations in at least three areas of major life activity and result in the need for services over an extended period of time.

We estimate that there are approximately 3.9 million persons with developmental disabilities in the United States, 2 million of whom are over the age of 18.

Persons served in residential facilities represent only a small percentage of this population; for example, about 146,000 persons reside in Medicaid-funded intermediate care facilities for the mentally retarded.

The Developmental Disabilities Act of 1984 established the following principles for the Developmental Disabilities program:

Persons who are developmentally disabled should be able to:

Exert control over their own lives;

Engage in income-producing work—including competitive employment—or perform work which will contribute to a household or community; and

Use community resources and live within that community.

The legislation which we administer contains four major components: Basic State Grants, Protection and Advocacy grants, University-Affiliated Facilities, and Special Project grants.

At the Federal level, the Administration on Developmental Disabilities coordinates with various departmental and other agencies that provide funding for services needed by the developmentally disabled. Our current coordination efforts include the Intradepartmental Work Group on Policies Affecting Mentally Retarded and Other Developmentally Disabled People and the Interagency Committee on Developmental Disabilities.

In addition, the Administration on Developmental Disabilities has engaged the private sector in promoting self-sufficiency for persons with developmental disabilities through its Employment Initiative.

President Reagan announced the Employment Initiative in November of 1983 as part of the National Decade of Disabled Persons.

In the first 2 years of the campaign, approximately 87,000 workers with developmental disabilities have been employed in private sector jobs. They will earn about $400 million in gross annual taxable wages, while the combined savings in public support costs and services will total nearly another $400 million.

This extraordinary accomplishment is due to the active support of corporations such as Radisson Hotels, Denny's Restaurants, the McDonalds Corporation, and trade associations, including the American Hospital Association, and the National Restaurant Association, among others.

The Employment Initiative Campaign has shown that, given proper support services, persons with developmental disabilities can be employed at work sites where persons without disabilities are employed.

We strongly support H.R. 1871 which would reauthorize the Developmental Disabilities Assistance and Bill of Rights Act.

This bill would:

Extend authorization of appropriations for programs under the Act for 3 years, authorizing such sums as necessary for each of fiscal years 1988, 1989 and 1990.

Add family support services as a priority service area in the Basic State Grant program. This proposal would expand and provide crucial supportive services to families who care for their developmentally disabled family member within the home. Family support services are defined as services which:

Strengthen the family's role as primary care givers;

Prevent out-of-home placement;

Reunite families with members who have been placed out of the home; and

Maintain family unity.

Family support services may include respite care, personal care, parent training and counseling, and other services which will support the well being of families of persons with developmental disabilities.

The bill would also clarify the definition of supported employment to stress competitive employment of developmentally disabled individuals at work sites where individuals without disabilities are employed. This proposal reaffirms our position that developmental-

ly disabled individuals should participate fully in competitive employment and not be limited to sheltered workshops or other protected positions designed exclusively for the developmentally disabled.

Another provision of the bill would broaden the category of family representatives on State Planning Councils to include relatives or guardians of formerly institutionalized persons with developmental disabilities. This provision would assist States in complying with the Planning Councils' composition requirements by expanding the available pool of parents or guardians eligible to serve on the Council.

In closing, I want to assure you that our policies have and will continue to focus on attaining the complementary goals of providing greater program authority at the State and local level, supporting improved program effectiveness, and recognizing the needs, potential, and accomplishments of persons with developmental disabilities.

Thank you, Mr. Chairman. I would be happy to answer any questions.

Mr. WAXMAN. Thank you very much.

[The prepared statement of Ms. Elder follows:]

STATEMENT OF JEAN K. ELDER, PH.D., ASSISTANT SECRETARY FOR OFFICE OF HUMAN DEVELOPMENT SERVICES-DESIGNATE

Mr. Chairman, I welcome the opportunity to appear before this distinguished subcommittee to discuss the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. I am especially pleased to be talking with this subcommittee following the first national celebration of Developmental Disabilities Awareness Month as proclaimed by President Reagan on February 26, 1987. Over 30 States and jurisdictions have issued proclamations in support of greater national awareness of the unique needs, accomplishments and potential of persons with developmental disabilities.

Mr. Chairman, we strongly support the administration's reauthorization legislation which has been introduced by Congressman Madigan. This bill, H.R. 1871, reauthorizes the Developmental Disabilities Assistance and Bill of Rights Act for 3 years. We are honored to have Mr. Madigan, the ranking member of this subcommittee, and a leader in the effort to provide strong support and services to the developmental disabilities population, as the sponsor of our legislation.

We want to thank you, Congressman Madigan, and all members of this subcommittee for the support given to the Developmental Disabilities program and the genuine concern shown for our citizens who are developmentally disabled.

THE DEVELOPMENTALLY DISABLED POPULATION

When Congress set out to help developmentally disabled people it was providing for one of the most vulnerable groups in the Nation. An individual is considered developmentally disabled when severe, chronic disabilities attributed to mental or physical impairments are manifest before age 22. Such disabilities must cause substantial limitations in at least three areas of major life activity and result in the need for services over an extended period of time. Possible limitations may occur in the areas of self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic independence. We estimate that there are approximately 3.9 million persons with developmental disabilities in the United States, approximately 2 million of whom are over the age of 18. Persons served in residential facilities represent only a small percentage of this population: for example, about 146,000 persons reside in Medicaid funded intermediate care facilities for the mentally retarded.

OVERALL PURPOSE OF THE DEVELOPMENTAL DISABILITIES PROGRAM

The Developmental Disabilities Act of 1984 established the following principles for the Developmental Disabilities Program:

Persons who are developmentally disabled should be able to:

- Exert control over their own lives;
- Engage in income producing work (including competitive employment) or perform work which will contribute to a household or community; and
- Use community resources and live within that community.

The Administration on Developmental Disabilities is charged to assist States to:

- Assure that persons with developmental disabilities receive the services necessary to enable them to achieve their maximum potential through increased independence, productivity, and integration into the community; and,
- Establish and operate a system which protects the legal and human rights of persons with developmental disabilities.

The legislation which we administer contains four major program components. It authorizes funds for:

1. Basic State Grants;
2. Protection and Advocacy Grants;
3. University Affiliated Facility Grants; and
4. Special Project Grants.

BASIC STATE GRANTS

Basic State Grants help States to plan, coordinate, and administer services for persons with developmental disabilities. Formula grants funds are awarded to each State to support the State Developmental Disabilities Planning Council. The State Council, comprised of representatives of major State and Federal programs, service providers, and developmentally disabled persons and their families, monitors the service delivery network and prepares a 3 year State plan. As part of that plan, each State must provide services in the area of employment-related activities. In addition, they may select up to two more of the following priority service areas:

- Case Management;
- Child Development Services;
- Alternative Community Living Arrangements.

In fiscal year 1985 the Basic State Grant Program served 55,675 persons. Funds from Basic State Grant have provided "seed money" to initiate new and innovative services. For example:

- Connecticut—A grant was awarded to the Corporation for Independent Living which expanded opportunities for the developmentally disabled to leave institutions and reside in the community. In fiscal years 1984-1986, 144 individuals were moved from State institutions to community settings.
- Utah—A grant was awarded which provided 500 days of 24-hour care and 600 hours of trained sitter services for families with a developmentally disabled member. This project provided respite care which was important to the well-being of the families and supported community integration.
- Washington—A grant was awarded which provided 17 special education parent advisory council training sessions in 26 school districts throughout the State. The training increased the involvement of parents in securing improvements in the quality of services for young developmentally disabled children.

PROTECTION AND ADVOCACY GRANTS

Protection and Advocacy grants are awarded by formula to State Protection and Advocacy agencies. These agencies must be independent from any entity which provides services to persons with developmental disabilities and must have the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of developmentally disabled individuals. The Protection and Advocacy System served 52,000 persons in fiscal year 1985, providing assistance with problems related to education, employment, transportation, vocational rehabilitation, medical services, abuse and neglect, housing, architectural barriers, and guardianship. In addition, thousands of disabled persons have received information and referral services from the Protection and Advocacy System.

UNIVERSITY AFFILIATED FACILITIES

Under the University Affiliated Facilities Program, grants are awarded to support a national network of 36 University affiliated facilities and 7 satellite centers. These facilities provide academic and professional training and ensure that there is a professional and paraprofessional workforce prepared to meet the service needs of the developmentally disabled. Approximately 57,000 individuals with developmental dis-

abilities and their families receive direct services each year from the University affiliated facilities and satellite centers.

SPECIAL PROJECT GRANTS

Special project grants are awarded through the HDS Coordinated Discretionary Funds Program to States, universities and non-profit organizations to provide financial assistance for developing new technology and applying innovative methods to support the independence, productivity, and integration into the community of persons with developmental disabilities. In FY 1986, the Administration on Developmental Disabilities' Special Project grants emphasized increasing opportunities for employment of persons with developmental disabilities. Special Project grants totalled $1,483,593 and addressed areas such as employee assistance programs, transition from school to work, employment models, and matching job vacancies and individual abilities.

FEDERAL COORDINATION EFFORTS

At the Federal level, the Administration on Developmental Disabilities coordinates with various departmental and other agencies that provide funding for services needed by the developmentally disabled, including the Health Care Financing Administration, the Social Security Administration, the Department of Education, and the Department of Housing and Urban Development.

One such coordination effort is the Intradepartmental Work Group on Policies Affecting Mentally Retarded and Other Developmentally Disabled people. The work group was established as a follow-up to the Report to Congress on Policies for Improving Services to Mentally Retarded and Other Developmentally Disabled Persons under Title XIX of the Social Security Act called for in the 1984 Developmental Disabilities Act. Recognizing the goals of independence, integration and productivity, and the obstacles that may prevent these goals from being realized, Secretary Bowen charged the work group to examine Federal policies and programs, including Medicaid-funded intermediate care facilities, and to recommend changes that will increase access to community living arrangements and encourage self-sufficiency. The work group, chaired by the Assistant Secretary for Planning and Evaluation, will forward its recommendations to the Secretary this year.

Another coordination effort involves participation in the Interagency Committee on Developmental Disabilities. This interagency Group coordinates and plans activities conducted by Federal departments and agencies as mandated by the Developmental Disabilities Act of 1984. The Committee, co-chaired by the Commissioner of the Administration on Developmental Disabilities and the Assistant Secretary for Special Education and Rehabilitative Services of the Department of Education, has identified two primary areas of emphasis: community living and supported employment.

PRIVATE SECTOR EFFORT: EMPLOYMENT INITIATIVE CAMPAIGN

The Administration on Developmental Disabilities has engaged the private sector in promoting self-sufficiency for persons with developmental disabilities through the Employment Initiative Campaign. President Reagan announced the Employment Initiative Campaign in November, 1983 as part of the National Decade of Disabled Persons. The campaign demonstrates that Americans with developmental disabilities can be a viable segment of the work force. The results to date have been most rewarding.

In the first 2 years of the campaign, approximately 87,000 workers with developmental disabilities have been employed in private sector jobs. They will earn about $400 million in gross annual taxable wages, while the combined savings in public support costs and services will total nearly another $400 million. This extraordinary accomplishment is due to the active support of corporations such as Radisson Hotels, Denny's Restaurants, the McDonalds Corporation, and trade associations, including the American Hospital Association, and the National Restaurant Association, among others.

The Employment Initiative Campaign has shown that, given proper support services, persons with developmental disabilities can be employed at worksites where persons without disabilities are employed.

REAUTHORIZATION

In order to continue our work to provide care, treatment and other services to persons with developmental disabilities, we strongly support H.R. 1871 which would

reauthorize the Developmental Disabilities Assistance and Bill of Rights Act. This proposal would:

● Extend authorization of appropriations for programs under the act for 3 years. Appropriations would be authorized for such sums as necessary for each of the fiscal years, 1988, 1989, and 1990.

● Add family support services as a priority service area in the Basic State Grant Program. This proposal would expand and provide crucial supportive services to families who care for their developmentally disabled family member within the home. Family support services are defined as services which:

—Strengthen the family's role as primary care givers;
—Prevent out-of-home placement;
—Reunite families with members who have been placed out of the home; and
—Maintain family unity.

Family support services may include respite care, personal care, parent training and counseling, and other services which will support the well-being of families of persons with developmental disabilities.

● Clarify the definition of supported employment to stress competitive employment of developmentally disabled individuals at worksites where individuals without disabilities are employed. This proposal reaffirms our position that developmentally disabled individuals should participate fully in competitive employment and not be limited to sheltered workshops or other protected positions designed exclusiely for the developmentally disabled.

● Broaden the category of family representatives on State planning councils to include relatives or guardians of formerly institutionalized persons with developmental disabilities. States have experienced increasing difficulty in identifying individuals willing to serve on the State planning councils due to the success of deinstitutionalization and the concomitant decrease in the available parent pool. This provision would assist States in complying with the planning councils' composition requirements by expanding the available pool of parents or guardians eligible to serve on the Council.

CONCLUSION

In closing, I want to assure you that our policies have and will continue to focus on attaining the complementary goals of providing greater program authority at the State and local level and supporting improved program effectiveness, in recognizing the needs, potential, and accomplishments of persons with developmental disabilities.

Thank you, Mr. Chairman, I would be happy to answer any questions.

Mr. WAXMAN. I understand that the administration endorses Mr. Madigan's bill which provides for a 3-year authorization of the DD program.

In fiscal year 1987, approximately $85 million was authorized for DD programs and $84 million appropriated.

The Consortium for Citizens with Developmental Disabilities has recommended that the authorization for fiscal year 1988 be raised to $105 million.

In contrast, the administration has requested an authorization of "Such funds as may be necessary" for fiscal year 1988.

How does the administration's request compare with the Consortium's? Can you give us a more precise budget recommendation?

Ms. ELDER. The administration's reauthorization authority has indicated "such sums as necessary." The Developmental Disabilities program is part of the Department's $2.2 billion generic appropriation request.

Mr. WAXMAN. Can you give us a more precise breakdown? We had $84 million appropriated last year. Do you expect an increase as high as $105 million?

Ms. ELDER. It is very difficult for me to say because we are talking about "such sums as necessary"——

Mr. WAXMAN. That is the authorization. You are going to go to the Appropriations Committee and tell them what you want. You are going to tell them what you think is necessary. We authorize the programs and let the Appropriation's Committee fill in the amount.

Sometimes we put an upper ceiling. Now you are recommending that we not specify an upper ceiling.

How much are you going to ask the Appropriations Committee for?

Ms. ELDER. I am not going to ask for a specific amount because it is part of the generic budget request.

Mr. WAXMAN. The generic budget request. What amount within that, if you get your generic budget request, will go to developmental disabilities?

Ms. ELDER. We will look at the generic budget request and consult with Congress. We will then make some decisions.

Mr. WAXMAN. Say you consult with Congress and Congress says you are right, whatever you wanted for that generic budget request, you get.

You get $2.2 billion; you get exactly what you asked for. Then you allocate these funds. How much of that will you allocate to developmental disabilities?

Ms. ELDER. At this time, we have not made a decision.

Mr. WAXMAN. How do you know to ask for $2.2 billion if you haven't—how do you give to the whole without knowing what the parts are?

Ms. ELDER. Initially the budget had line items.

Mr. WAXMAN. What did you recommend for DD?

Ms. ELDER. I don't remember. I would be glad to get it for the record.

Mr. WAXMAN. Do you know how much was recommended?

Mr. STOVENOUR. No, sir.

Ms. ELDER. I would prefer to submit that information for the record.

Mr. WAXMAN. That is reasonable.

[The following information was submitted for the record:]

The initial Administration on Developmental Disabilities fiscal year 1988 budget request (prior to the generic appropriation request) was as follows:

	Fiscal year 1988
Basic State Grants	50,250,000
Protection and Advocacy	11,000,000
UAF's and Special Projects	9,000,000
	70,250,000

Mr. WAXMAN. Do you know whether it was more or less than what was appropriated for 1987?

Ms. ELDER. It was level funding.

Mr. WAXMAN. So you are asking the same amount?

Ms. ELDER. That is what I remember.

Mr. WAXMAN. Would you care to comment on the American Association of University-Affiliated program's proposal to establish university-affiliated facilities in every State?

Ms. ELDER. I would be glad to comment on that. Given that I was trained at a university-affiliated facility, I understand what the program is all about and I feel that the training the university-affiliated facilities provide is very important to people who are and who serve the developmentally disabled.

I must also share with you that while there are great merits in the UAF program, we question whether a UAF is really necessary in every State.

Let me go back and give you a historical vignette about what happened when I was the Commissioner of the Administration on Developmental Disabilities.

We were looking to expand the UAF network, but looking to expand that network within reason. An announcement was published in the Federal Register in May 1984 and we proposed expansion within certain criteria. One of the criteria was that if a State did not have a UAF and if they had a population base of 2 million or more, then they could respond to the announcement.

Eight States that did not have a UAF and that met the population base came in. Then we said to them you have to find yourself an ongoing UAF to be your host. For example, the Colorado UAF could have been a host to Arizona.

We then funded the host university-affiliated facility to do a feasibility study of establishing a UAF at some university in the applicant-State.

In the applicant-State, there was usually more than one State university and so there was a little jockeying about who was to get the UAF: "I have this kind of faculty and you have that kind", and "I have better relationships with the State Government", et cetera.

Seven of these eight States found a host and went through the feasibility process. Of those seven, we funded three new UAF's.

Mr. WAXMAN. You don't think there ought to be one in every State?

Ms. ELDER. I don't know if there is a simple yes or no answer to that question. I think it is important that you establish a process and you look at whether there is a need; can these needs be addressed by the ongoing structure that exists or do we need a UAF in every State? For example, in your home State, we have more than one. Do we need more than one in California? Do we need more than one in New York?

When we look at the present system, if you go back historically, the UAF's were hard to sell because it was a new concept. Now this discipline has solidified and there is a real sense of what we do to train people and more people are interested.

How do we best meet the training needs? I am not sure if putting a UAF in every State is going to take care of it.

I think we have to be more disciplined in our strategy to get in place the best structure in this Nation. I don't suggest that we go slowly or drag our feet, but we must be clear as to what we are trying to do, so we can provide quality service, do good research, and deliver excellent service.

Mr. WAXMAN. I would like you to submit for the record information on the extent of compliance by State Planning Councils and Protection and Advocacy Systems with annual reporting requirements for fiscal years 1985 and 1986.

Ms. ELDER. I would be glad to do so.

[The following was submitted for the record:]

The State Planning Councils and the Protection and Advocacy systems have been very responsive in complying with the annual reporting requirements established by the 1984 amendments. For both fiscal year 1985 and 1986, 90 percent of the Councils and the Protection and Advocacy systems submitted annual reports on or before the due date of January 1. The remaining 10 percent were submitted by April 1 of each year.

Mr. WAXMAN. Section 107 of the Developmental Disabilities Act and Bill of Rights Act requires the Secretary to submit a report to the Congress on activities under the program for the previous year.

What is the status of this report for fiscal year 1986?

Ms. ELDER. It is in departmental clearance and I am hopeful that it will be here very shortly.

I would like to mention that although we were not required to do an annual report last year, we did submit one. That was something that I wanted to do when I was Commissioner, even though Congress had given us a year to figure out how we were going to do it. We did a fine job on the first year's report and this year's report is good as well.

Clearance is not always at the rate that we would like it to be. I think you will be very pleased when you receive it and I am sorry that it is delayed.

Mr. WAXMAN. The Consortium for Citizens with Developmental Disabilities has prepared a comprehensive document recommending revisions in the Developmental Disabilities Assistance and Bill of Rights Act.

Have you had a chance to review the Consortium's proposal? Did the Department have the opportunity to review these recommendations prior to forwarding its legislative proposal to the Congress?

Would you submit for the record the Department's comments and analysis of the Consortium's recommendations?

Ms. ELDER. Yes, I saw the report in various stages. They were working diligently on their recommendations at the same time we were working diligently on our legislative proposals. I have reviewed the Consortium report.

For example, the question on UAF's is in that report and clearly it reflects one viewpoint.

Another recommendation that the Consortium is making to Congress is that we eliminate the employment mandated priority service area provision within the DD legislation.

I would highly recommend that you really think that one through. I think we have just begun to prove that people, regardless of a disability, can be gainfully employed with the right kind of supports. That takes a lot of tough sledding.

There are attitudinal changes; for example, convincing businessmen who have never hired anyone that is disabled that their insurance rates won't go up. We have made a difference by having the employment component in the DD legislation.

I know the Consortium has suggested that employment not be a mandated priority service area for DD Councils. I suggest that you look at that thoroughly.

Other pieces are not that simple. I think we should think collectively about our best strategies.

Mr. WAXMAN. Let me ask you this. I do want to get all those points on all the recommendations, but give it to us for the record so we can evaluate it.

We are not going to move a bill until we evaluate it.

[The following information was submitted for the record:]

I have reviewed the recommendations made by the Consortium for Citizens with Developmental Disabilities (CCDD) regarding reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act and have the following comments on the major changes proposed by CCDD: (1) CCDD has recommended that employment related services for the Basic State Grant program no longer be a mandated priority service. As I noted in my testimony I recommend that Section 122(b)(4)(B)(ii) of the Developmental Disabilities Assistance and Bill of Rights Act, as amended, remain as currently written; thereby maintaining employment related activities as a mandated priority service area for the Basic State Grant program; (2) CCDD has recommended that a State have the option of developing a State priority service area under the Basic State Grant program. I am aware that individual States may feel that they have unique service needs that could be best addressed through the priority service provision. However, the current legislated priority service areas (alternative community living arrangement services, employment related activities, child development services and case management services) already provide for developing a State plan which ddresses individual State needs. Therefore, a legislative change is not necessary; (3) CCDD has recommended that the State Plan should indicate what resources are available in the State for people with developmental disabilities who do not have mental retardation. The State plans already address the service needs of all developmentally disabled individuals. To specifically identify the resources for developmentally disabled individuals who do not have mental retardation is a categorical approach which diminishes the intent of the widely accepted functional definition. In addition, such a reporting requirement would be burdensome to the States; (4) CCDD has recommended that the UAF program be expanded to include a UAF in every State. As I noted in my testimony, there are merits to expanding the UAF Network but such an expansion must be done in accord with a well-reasoned process designed to elicit the highest quality programs, capable of fulfilling UAF goals and objectives, while avoiding redundance; (5) CCDD has recommended funds for specific areas of interest for both the UAF program and Special Projects. Earmarking money for special areas through legislation limits program flexibility to respond to both current and future issues in support of people with developmental disabilities. Our present system welcomes and encourages suggestions from the field regarding topical areas to be funded as Special Projects; (6) CCDD has recommended that a carryover of 10 percent of the yearly allotments for the Protection and Advocacy systems be allowed. The Protection and Advocacy agencies operate on 100 percent Federal funding so that there may be problems for these agencies if there is a significant delay in the annual appropriation at the beginning of the fiscal year. However, there is no issue when funds are appropriated and awarded on a timely basis. Therefore, I do not believe a change to the legislation is necessary; (7) CCDD has recommended that the language permitting the "provision of specialized services" in the priority area should be deleted and the activity permitting "model service programs" should be modified to clarify that such programs are for demonstration purposes (e.g., model demonstration programs). I believe the current legislative language should be retained so that States have the flexibility to fund whatever type of services it determines is needed. Also, States should be able to continue to fund "model service programs" if they so wish. CCDD's proposal would force States to fund only model service programs as narrowly defined by CCDD, and (8) CCDD has recommended that language to include "policy analysis and educating policy makers" should be added to the definition of the term "service activities." Under the current statute DD Councils already have the authority to carry out the activities described by CCDD. However, these activities must be supported out of the portion of funds allocated to the State for planning activities (35 percent provision). I see no problem with defining these types of activities as service activities as long as they are not considered service activities

under the priority services. I would not concur with spending priority service funds on these types of activities (65 percent provision). The types of activities to be conducted under the priority services area should remain as currently written in the legislation.

Mr. WAXMAN. Concerns have been expressed about the inadequacy of data collection activities by the Department. We have heard the criticism that current collection activities with respect to developmental disabilities are inadequate to assist States and the Federal Government in assessing the need, availability and effectiveness of services.

Do you agree? What do you think of the Consortium's proposal to earmark $1 million of funds appropriated for the Section 161 special project grants for this purpose?

Ms. ELDER. That is a two-part question. To the second part of your question, my answer is no, but I don't want that to sound simplistic. I don't like earmarks. We don't have very much discretionary money. If we are going to call it discretionary money, then people should not keep earmarking it for something that they perceive to be the best thing for us to do.

My concern about earmarking is that we have had to struggle to bring forward the best R&D projects with very little money.

Responding to the first part of your question, data collection within developmental disabilities far outreaches what is done in most other programs. That does not mean that we are doing the very best job, but we have made great gains and much of it was done using external data collection methodology.

For example, we have funded a number of universities to collect data for us and then to give us information that helps policymakers and other people interested in this program make better decisions.

I am not sure if an earmark would provide the kind of products we are now getting.

Mr. WAXMAN. Earlier this month, Senator Thurmond introduced S. 926, a bill establishing a national computer system to provide information to parents on the availability of specialized services for developmentally disabled and chronically ill children.

The system would list services available from State agencies as well as voluntary organizations, parent support groups, private associations and hospitals.

Are you aware of this proposal? Is such a national system necessary?

Ms. ELDER. I am aware of the proposal. Some of the work that led to this bill was funded by our discretionary money in the Administration on Developmental Disabilities. It was a response to a priority area concerning how to best make information available so that people could access it and make good decisions.

Again, if we had had a lot of earmarks, maybe we wouldn't have been able to fund the precursor of the Thurmond bill.

Do we need this type of national system? I have seen a part of the Senator's request, but we have not thoroughly investigated all of what that legislation is suggesting.

If you could give me a week, I would be glad to submit a response for the record. I think we need to align this proposal with the Baby Doe systems and other systems we have to make certain

that they are complementary and not duplicative. I would be glad to do that for you.

Mr. WAXMAN. We will look forward to receiving all the information that we have asked for for the record. We appreciate your testimony today.

[The following information was submitted for the record:]

The Department is working on a bill report on S. 926, a bill to amend the Developmental Disabilities Assistance and Bill of Rights Act to provide grants for the operation of the National Information System for Health Related Services. I will send a copy of the bill report to Chairman Waxman as soon as Departmental and OMB clearance is completed.

Mr. WAXMAN. Our next witnesses will testify as a panel. Orville Karan is from the Waisman Center on Mental Retardation and Human Development, representing the American Psychological Association; Ms. Eileen Cubarney is representing United Cerebral Palsy Associations, Inc.; Dr. Michael Guralnick, is president, American Association of University Affiliated Programs; Catherine A. Raggio, is executive director of the Maryland Developmental Disabilities Council, Developmental Disability Council; and Gayla Peach, is director, Office for Public Advocacy, Division for Protection and Advocacy.

We welcome you to the hearing and your prepared statements will be made a part of the record.

Mr. Karan, why don't you begin.

STATEMENTS OF ORVILLE C. KARAN, ON BEHALF OF AMERICAN PSYCHOLOGICAL ASSOCIATION; EILEEN CUBARNEY, ON BEHALF OF UNITED CEREBRAL PALSY ASSOCIATIONS, INC.; MICHAEL GURALNICK, PRESIDENT, AMERICAN ASSOCIATION OF UNIVERSITY AFFILIATED PROGRAMS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES; CATHERINE A. RAGGIO, ON BEHALF OF NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITY COUNCILS; AND GAYLA O. PEACH, DIRECTOR, OFFICE FOR PUBLIC ADVOCACY DIVISION FOR PROTECTION AND ADVOCACY

Mr. KARAN. Thank you very much.

On behalf of over 87,000 psychologists throughout the country, the American Psychological Association appreciates the opportunity to share our views with the subcommittee regarding the reauthorization of the Developmental Disabilities Act.

First, we would like to express our support for the legislation, particularly the interdisciplinary focus which brings together professionals, consumers and agency representatives who are working to improve the lives of our Nation's developmental disabilities citizens. This subcommittee has a strong track record of leadership and advocacy for developmental disabilities persons, and we are proud to support the work that the subcommittee has done.

Our forefathers envisioned a country in which "all men are created equal," and for many, America has become the "land of opportunity." Most children are encouraged to believe that with enough ambition and hard work they can become whatever they want to be; that is, unless they are developmental disabilities. For many of these youngsters, theirs is the land of limited opportunity.

Most adults who are developmental disabilities can be found in one of two distinct groups—those who fit the limited community options which are available and those who do not. This latter group contains many who are needlessly confined to segregated settings or without any services at all.

It has only been in the last few years that this problem has even reached our national awareness. Partly because of our recent medical advances, which have resulted in saved lives and greater longevity for those who most certainly would have died less than a decade ago; partly because of our school systems, which provide public education to all youngsters, regardless of the extent of their handicapping conditions; and partly because of our technological breakthroughs which have contributed to overwhelming demonstrations of competence and have simultaneously raised our expectations about what people with developmental disabilities can accomplish, our society is capable of preparing a healthier, better educated, more competent population of developmental disabilities citizens.

Yet, many are entering an adult service system which is incapable of maintaining, let alone, capitalizing on this momentum.

A major part of the problem is that the adult service system in this country has been completely overwhelmed by the multiplicity of new and different demands that have been created by the breakthroughs and opportunities society has created in some of its other systems. The resulting costs to society in lost human potential and forced dependency are staggering.

The two most often identified major gaps in our adult services systems are: (1) the lack of central coordination and service delivery; and (2) the lack of a single resource for long-term funding and employment-related services. These have been addressed in national studies without resolution.

As we attempt to respond to the community integration challenges ahead, we must be careful to avoid one of the major conceptual and procedural errors of the past, namely, that individuals with developmental disabilities be required to adapt to a limited range of community options.

Under these circumstances, when a mismatch occurred, there was a tendency to blame the victim. Today we are just beginning to recognize that instead of simply attributing failure to the individual, components of the service system must be modified.

It is becoming clearer that one's community placement success depends not on the degree of their handicap, but rather on what their community is willing and able to provide.

In this reauthorization process, I ask you to recognize that above all the Developmental Disability Act is concerned not merely with rights, employment, training or research, but most importantly with individual persons; persons who, yes, require access to both quality services and to the mainstream of our society, but also who together with their families must receive the necessary support they, as individuals, need to fully grow and develop within the family and other societal systems.

Indeed, if the individual person with developmental disabilities is not prepared to take advantage of these systems, his or her ability

to reach their full potential for participation in society will certainly be limited.

The Demonstration Projects I urge you to include in the reauthorized DD Act speak directly to the needs of the individual, and these projects are designed to meet very understandable needs.

Imagine for just a moment the tremendous emotional stress the parents of a newborn, at-risk infant face as they recognized their child's disability. For their child to have the chance to take full advantage of the opportunities we know society can and must provide, the parents and the child need the professional guidance and support of skilled psychologists.

And what of the individual who is leaving the place—perhaps the only place—he knows—the institution—for a new life in the community. We have all seen the reluctance and indeed often the resistance of such individuals and their families to such a move.

In a word, they are afraid. They know at least the certainly of the institution, whatever its inadequacies, and they are fearful of the unknown and, at least to them, uncertain future in a society they have learned sometimes doesn't seem to care.

The skilled professional psychologist can properly prepare institutionalized individuals and the families to look forward to the opportunities for growth that community placement offers and thus be prepared to take full advantage of an integrated lifestyle.

So, too, the young developmental disabilities adult graduating from special education needs to know he or she can successfully manage both living and working in the community.

This transition as we have learned is often very difficult and the recent ICD/Harris Poll of employers suggested that persons with disabilities seeking employment or advancement are often hampered by diminished self-image.

Can we deny that recognizing and accepting one's disability in an integrated living and working situation is essential for success? And if not, can we fail to see the critical role the skilled psychologist must play in preparing the person with an extra burden—an extra challenge—to make the successful transition?

Finally, we must not forget that group who often are not thought of when we speak of persons with disabilities—the aged. They together with their families need special support and counsel to see how their lives in the community can be meaningful and rewarding.

The challenge of the future is to provide for a coordinated, collaborative service system that will enable the handicapped person to receive services in an expeditious and coordinated manner.

The American Psychological Association would like to recommend the inclusion of the attached special projects in the reauthorized legislation so that some of the problems we have outlined can begin to be addressed.

Thank you for this opportunity, Mr. Chairman, to present our views.

Mr. WAXMAN. Thank you very much.

[The statement of Mr. Karan follows:]

STATEMENT OF ORVILLE C. KARAN

On behalf of over 87,000 psychologists throughout the country, The American Psychological Association appreciates the opportunity to share our views with the subcommittee regarding the reauthorization of the Developmental Disabilities Act.

First, we would like to express our support for the legislation, particularly the interdisciplinary focus which brings together professionals, consumers and agency representatives who are working to improve the lives of our Nation's developmentally disabled citizens. This subcommittee has a strong track record of leadership and advocacy for developmentally disabled persons, and we are proud to support the work that the subcommittee has done.

Our forefathers envisioned a country in which "all men are created equal," and, for many, America has become the "land of opportunity." Most children are encouraged to believe that with enough ambition and hard work they can become whatever they want to be; that is, unless they are developmentally disabled. For many of these youngsters, theirs is the land of limited opportunity.

Most adults who are developmentally disabled can be found in one of two distinct groups—those who fit the limited community options which are available and those who do not. This latter group contains many who are needlessly confined to segregated settings or without any services at all.

It has only been in the last few years that this problem has even reached our national awareness. Partly because of our recent medical advances, which have resulted in saved lives and greater longevity for those who most certainly would have died less than a decade ago; partly because of our school systems, which provide public education to all youngsters, regardless of the extent of their handicapping conditions; and partly because of our technological breakthroughs which have contributed to overwhelming demonstrations of competence and have simultaneously raised our expectations about what people with developmental disabilities can accomplish, our society is capable of preparing a healthier, better educated, more competent population of developmentally disabled citizens. Yet many are entering an adult service system which is incapable of maintaining, let alone capitalizing on, this momentum.

If we have a technology that can contribute to an elderly population of developmentally disabled citizens who are fit, well, and involved, then who do we offer them instead precarious health, life in costly and complex facilities, and meaningless activity or unproductive roles in society? If we can prepare these youngsters for roles as contributing members of society, then why are more than 80 percent of them unemployed or underemployed within 1 year after completing their education? And, if we can now save the lives of catastrophically handicapped infants, then why do we, in turn, compromise the lives of their parents who often must shoulder the lifelong responsibility for their care alone?

A major part of the problem is that the adult service system in this country has been completely overwhelmed by the multiplicity of new and different demands that have been created by the breakthroughs and opportunities society has created in some of its other systems. The resulting costs to society in lost human potential and forced dependency are staggering.

The two most often identified major gaps in our adult services system are: (1) the lack of central coordination of service delivery, and (2) the lack of a single resource for long-term funding and employment-related services. These have been addressed in national studies without resolution.

THE VARYING NEEDS AND CHARACTERISTICS OF THE POPULATION

Congressional data indicate that approximately 8.8 percent of the population receive assistance for special education each year. Stimulated by PL 94-142, passed in 1975, we are now finding an unprecedented number of students with disabilities who are "graduating" from public school systems each year. It is estimated that 250,000-300,000 students graduate from special education programs annually of whom over 90,000 are developmentally disabled. These young adults, having been exposed to educational opportunities that were simply unavailable a decade ago, are a qualitatively different group of people than the generations which preceded them. Generally speaking, this new breed of young adults at all levels of handicap have more skills, more normal life experiences, and more potential than their earlier counterparts. Both they and their parents rightfully expect the same opportunities for further education and jobs that are available to their nonhandicapped peers.

As these recent graduates push the adult system from one end, residents of large public institutions, who are slowly being returned to the community, are pushing it

from another end. It has been estimated that 6,000 individuals leave public-operated institutions each year to join those in community settings.

There are today approximately 110,000 mentally retarded and other developmentally disabled persons now living in public residential facilities. Although this represents only about 6 percent of the total number of such persons, they account for almost 41 percent of the total expenditure of Federal dollars spent on developmental disabilities in this country, or roughly $2.8 billion annually.

Many of these people grew up before the passage of PL 94-142 and therefore missed training opportunities which today are all but taken for granted. Theirs was the era of custodial care, and the primitive behaviors they acquired may have helped them cope with their impoverished institutional environments. Such behaviors are now inconsistent with successful integration within community settings. Service providers have really not had much experience serving these adults nor have they been well represented in the impressive community integration demonstrations to date.

Then there are those who have lived at home all their lives with their families. Most of these adults are middle aged or older, and because of the age, health, and/or death of their parents, are now just coming to the attention of the adult service system.

As advancements in medical technology and habilitative programming have dramatically impacted the life expectancy of these persons, a significant increase has emerged in the numbers of persons with developmental disabilities reaching old age. Yet, for many of them, in order to sustain their residence in the community, they must continue working when most of their nonhandicapped peers have long since retired.

RESPONDING TO THE CHALLENGES

As we attempt to respond to the community integration challenges ahead, we must be careful to avoid one of the major conceptual and procedural errors of the past, namely, that individuals with developmental disabilities be required to adapt to a limited range of community options. Under these circumstances, when a mismatch occurred, there was a tendency to blame the victim. Today we are just beginning to recognize that instead of simply attributing failure to the individual, components of the service system must be modified. It is becoming clearer that one's community placement success depends not on the degree of their handicap, but rather on what their community is willing and able to provide.

Many individuals, including professionals, parents, peers, paraprofessionals, even the person on the street, all play important direct or indirect roles in providing this support. Ways must be found to maximize the helpful participation of a wide variety of potential support people because a social life and interactions with others are important for individuals who are developmentally disabled. Individuals with social ties have been found to show less vulnerability to stress and to be more socially adjusted. Social support appears to be a vital ingredient for positively contributing to one's mental and physical health.

The family is obviously an important part of this support network, and the role family members play is a critical factor in one's successful community integration. Through training and support, parents can become the "glue" that reduces the fragmentation so notorious in adult services and can ultimately contribute to the best community options for their family member.

Among those who fail to adjust to community environments there is a high prevalence of associated mental health difficulties. In fact, the prevalence of psychopathology among persons who are developmentally disabled is four to five times that of the normal population, and anywhere from 33 percent to 100 percent of those who fail in their community placements demonstrate obvious mental health difficulties. A recent national survey of community residential facilities for people who were developmentally disabled reported mental health difficulties to be the single most frequently identified condition among those residents with additional handicapping conditions.

Meeting the mental health needs of people who are developmentally disabled is a laudable "quality of life" goal, but, in fact, community service personnel in general currently neither have the skills or desire to effectively treat these mental health difficulties nor the service delivery systems to provide the type and continuity of resources required for effective treatment. Improving the adequacy and availability of such resources will depend on better training for both specialized and generic service providers.

In this reauthorization process, I ask you to recognize that above all the Developmental Disability Act is concerned not merely with rights, employment, training or research but most importantly with individual persons; persons who, yes, require access to both quality services and to the mainstream of our society but also who together with their families must receive the necessary support they, *as individuals, need* to fully grow and develop within the family and other societal systems. Indeed, if the individual person with developmental disabilities is not prepared to take advantage of these systems, his or her ability to reach their full potential for participation in society will certainly be limited.

The Demonstration Projects I urge you to include in the reauthorized D.D. Act speak directly to the needs of the *individual*, and these projects are designed to meet very understandable needs.

Imagine for just a moment the tremendous emotional stress the parents of a newborn, at-risk infant face as they recognize their child's disability. For their child to have the chance to take full advantage of the opportunities we know society can and must provide, the parents and the child need the professional guidance and support of skilled psychologists.

And what of the individual who is leaving the place—perhaps the only place—he knows—the institution—for a new life in the community. We have all seen the reluctance and indeed often the resistance of such individuals and their families to such a move. In a word, they are afraid. They know at least the certainty of the institution, whatever its inadequacies, and they are fearful of the unknown and, at least to them, uncertain future in a society they have learned sometimes doesn't seem to care. The skilled professional psychologist can properly prepare institutionalized individuals and the families to look forward to the opportunities for growth that community placement offers and thus be prepared to take full advantage of an integrated lifestyle.

So, too, the young developmentally disabled adult graduating from special education needs to know he or she *can* successfully manage both living and working in the community. This transition as we have learned is often very difficult and the recent ICD/Harris Poll of employers suggested that persons with disabilities seeking employment or advancement are often hampered by diminished self image. Can we deny that recognizing and accepting one's disability in an integrated living and working situation is essential for success? And, if now, can we fail to see the critical role the skilled psychologist must play in preparing the person with an extra burden—an extra challenge—to make the successful transition?

Finally, we must not forget that group who often are not thought of when we speak of persons with disabilities—the aged. They together with their families need special support and counsel to see how their lives in the community can be meaningful and rewarding. Without such recognition, an institutional placement is often the only option seen. As we know, it is an option that is terribly expensive in both human and economic terms. Psychological services can mean the difference between continued participation in society and a withdrawal from society to the closed and regressive life of a segregated institution.

The challenge of the future is to provide for a coordinated, collaborative service system that will enable the handicapped person to receive services in an expeditious and coordinated manner. The American Psychological Association would like to recommend the inclusion of the attached special projects in the reauthorization legislation so that some of the problems we have outlined can begin to be addressed.

Thank you for this opportunity to present our views.

Demonstration Projects for the Developmental Disabilities Act

The following is draft language to be inserted as Section 162(a)(1)(D) of the Developmental Disabilities Act:

(d) Of which at least four shall be to demonstrate the effectiveness of a range of psychological services for developmentally disabled persons including:

(1) One project providing psychological services to children from birth to 2 years of age, inclusive, (and their families) who have or are at risk for developmental disabilities as a means to enhance their physical, social, emotional, and/or cognitive development and minimize the degree of future impairment. This project is to be coordinated with the lead agency implementing Part H of PL 99-457;

(2) One project providing psychological services for developmentally disabled individuals (and their families) to facilitate their transition from institutional settings to independent living arrangements in the community;

(3) One project providing psychological services for developmentally disabled young adults (and their families) who are preparing to leave special education to increase their potential for community participation and gainful employment;

(4) One project providing psychological services to aged developmentally disabled individuals residing with their families in the community to maintain their functional level so as to prevent the need for placement in an institutional care setting.

For FY 1988, FY 1989 and FY 1990, $1.5 million is authorized per project. Only departments or schools of psychology that grant doctoral degress are eligible for such projects. Projects are to be awarded for a 3-year period.

Mr. WAXMAN. Ms. Cubarney.

STATEMENT OF EILEEN CUBARNEY

Ms. CUBARNEY. Mr. Chairman, my name is Eileen Cubarney. I am the mother of six children. I have been engaged in advocacy on behalf of children and adults with disabilities for over 25 years.

I am speaking today on behalf of United Cerebral Palsy Associations, Inc., Epilepsy Foundation of America, and seven other national organizations on behalf of individuals with the most severe disabilities.

We share a common vision of an American society that provides opportunities for school-age children with severe disabilities to be educated in public schools in a way that promotes interaction with their non-handicapped peers; for adults with severe disabilities to live at home and in their home communities enjoying the benefits of friendship and continuing personal relationships.

My remarks today will be to paint for you a portrait of an American family: my family. The portrait is typical of thousands of families across the country who have sons and daughters with substantial functional limitations as defined in the Developmental Disabilities Act.

My testimony will describe the barriers we face as families seeking adequate and appropriate supports to enable our sons and daughters to learn, live and work in their home communities.

My son David is 21 years old. He has a diagnosis of cerebral palsy and is further labeled as having quadraplegia. He can talk but he cannot walk, feed himself, dress himself, or attend to his bodily functions.

He has average to above-average intelligence. Had we listened to the professionals when he was a baby and placed David in an institution, our family would have been financially solvent today, and I believe David would have been the vegetable that they diagnosed him as.

I present to you his graduation picture. He will graduate this year from his local school.

Instead, we chose to raise David at home and learn first hand about the struggles to earn his right of citizenship.

Our family has had only 4 vacations in 18 years. Although Pennsylvania has a very large program of family support and respite services, David did not have the right label to access the system. We chose not to try and find a clinician who would relabel David as "mentally retarded"—many parents chose that route—in order to access these services. To do so was too much of a compromise of his dignity and our integrity.

We paid for his therapies in his infant years and he attended the UCP nursery school which was funded by donations from the Elks Club. At age 5, he attended a private school for a number of years, which the public school paid a per diem and we paid the rest of the tuition which exceeded the mortgage payment on our home.

At age 13, with David's and our rights articulated in P.L. 94-142, the Education for all Handicapped Children's Act of 1975, and with the ongoing assistance and support of Congressman Walgren and his staff in Pittsburgh and an attorney whom we paid, we filed and won both a due process and a civil rights suit against the school district in order to have David removed from "special school" where he learned almost nothing and sent to a regular school with children of his own age who were not handicapped. David was the first student with quadraplegia to be "mainstreamed" in our community.

We won, but the special school was so unprepared to meet his needs that they wanted to offer him a janitorial training program.

Our own school district was so disgusted with this recommended that they said they would take him into regular school with children of his age who were not handicapped.

He presently attends, in addition to his regular education program, 2 days a week the United Cerebral Palsy Independent Living program where he is learning how to direct his own life and how to direct his own life and how to manage his attendant.

My school district has chosen to pick up the transportation costs for this and UCP pays for the educational program.

He began receiving attendant services in 1985 as a result of Pennsylvania's pilot program, which still only exists in six counties of our State.

Other than the public schooling that he has received, 1 wheelchair in 20 years, my son has received no government funding of any kind.

The attendant services have changed our family's role from that of David's constant care givers to mother, father, brother and sister. This service has allowed me the opportunity to go to work for the first time in over 20 years and assist my husband's modest income in supporting our 4 children in college and to earn my own degree.

I am employed in the Rehabilitation Technology Center at the Rehabilitation Institute of Pittsburgh.

I am involved daily with what is being achieved through technology for people like David and countless others with severe functional limitations with and without medical impairments. Yet, how many individuals go without, go begging, and I see this daily, or are denied access to these and other necessary support services because their State has not yet chosen to put in place a service delivery system for all persons with developmental disabilities?

If you have quadraplegia in the State of Pennsylvania and you are unlucky enough to not have private means, you cannot own an electric wheelchair, you cannot move yourself in or out of the sunlight that streams into your window.

None of us owns the space that we presently occupy. Any of us today or any of our family members could be in like circumstances.

I call to your attention that the intent of the law is not being met consistently in my State and in other of the 50 States...."to assist States to (a) assure that persons with developmental disabilities receive the care, treatment, and other services necessary to enable them to achieve their maximum potential through independence, productivity, and integration into the community..."

The original intent of Congress in 1963 was to develop services to meet the needs of people with mental retardation. In 1970 and 1975, this intent was extended to people with other disabilities with similar service needs. And in 1978, the language was modified to assure that just persons with the most substantial disabilities received services.

This is not happening in some of the States in this country.

The definition included in the 1978 Act, Public Law 95-602 and which continues today has three major differences from the 1975 Act, which are, no specific diagnostic categories or labels are used other than "mental and physical impairment."

Two, the age limit for onset of the disability was raised from 18 to 22; and

Three, the necessity of a substantial functional limitation in three or more areas of major life activity.

We have come a long way, but we believe it is now time to reconcile Federal intent with State policy. As Dr. Elizabeth Boggs, a national expert on developmental disabilities, stated upon New Jersey's adoption of the Federal definition into State statute in 1985, "We have had a non-accessing population of people—specifically, young adults with severe physical disabilities—who have had nowhere to go for assistance in putting it all together. These people really deserve to have an agency that can work for them..."

I would enlarge that to cover from birth through young adults.

I urge you to (1) reaffirm that State councils be involved in the system reform necessary within their respective States so that each State adopt the Federal definition in a timely manner; and (2) assure that each of the States meet the intent of the law by assigning the most appropriate agencies to be responsible and accountable to provide access to the full range of support services for individuals with developmental disabilities without mental impairments.

Until that time, the promise of the Act will remain unfulfilled.

Over 1 million citizens will continue to be more dependent than necessary on our resources and robbed of their human dignity and opportunity to contribute to community life.

I ask you please do not tell me that our 20-year fight has been in vain. Please do not tell my son that his years of valiant effort have earned for him a prison sentence in an institution for a crime he did not commit.

Thank you.

Mr. WAXMAN. Thank you.

Your son is not only fortunate to have you as a mother, but all the people with disabilities are fortunate to have you battling for them.

[The prepared statement of Ms. Cubarney follows:]

STATEMENT OF EILEEN CUBARNEY

My name is Eileen Cubarney. I am the mother of six children. I have been engaged in advocacy on behalf of children and adults with disabilities for over 25 years. I am speaking today on behalf of United Cerebral Palsy Associations, Inc., Epilepsy Foundation of America, and seven other national organizations on behalf of individuals with the most severe disabilities. We share a common vision of an American society that provides opportunities for school age children with severe disabilities to be educated in public schools in a way that promotes interaction with their nonhandicapped peers; for adults with severe impairments to be employed in diverse settings earning a competitive wage; and for all children and adults with severe disabilities to live at home and in their home communities enjoying the benefits of friendship and continuing personal relationships.

My remarks today will be to paint for you a portrait of an American family: my family. The portrait is typical of thousands of families across the country who have sons and daughters with substantial functional limitations as defined in the Developmental Disabilities Act.

My testimony will describe the barriers we face as families seeking adequate and appropriate supports to enable our sons and daughters to learn, live, and work in their home communities.

My son David is 21 years old. He has a diagnosis of cerebral palsy and is further labelled as having quadraplegia. He can talk but he cannot walk, feed himself, dress himself or attend to his bodily functions.

He has average to above average intelligence. Had we listened to the professionals when he was a baby and placed David in an institution our family would have been financially solvent today. Instead we chose to raise David at home and learn first hand about the struggles to earn his *right of citizenship.*

Our family has had only four vacations in 18 years. Although Pennsylvania has a very large program of family support and respite services, David did not have the right label to access the system. We chose not to try and find a clinician who would relabel David as "mentally retarded" to acces these services. To do so was too much of a compromise of his dignity and our integrity.

We paid for his therapies in his infant years and he attented the UCP nursery school which was funded by donations from the Elks Club. At age five he attended a private school for which the public school paid a per diem and we paid the rest of the tuition which exceeded the mortgage payment on our home.

At age thirteen with David's and our rights articulated in P.L. 94-142, the Education for all Handicapped Children's Act of 1975, and with the ongoing assistance and support of Congressman Walgren and his staff in Pittsburgh and an attorney whom we paid, we filed and won both a due process and a civil rights suit against the school district in order to have David removed from "special school" where he learned almost nothing and sent to a regular school with children of his own age who were not handicapped. David was the first student with quadraplegia to be "mainstreamed" in our community.

We won, but the school was so unprepared to meet his needs that they wanted to offer him a janitorial training program. With the help of local UCP staff an appropriate education plan was developed. For the past 2 years, as the result of another fight, David receives his education 2 days a week at the Independent Living Center where he is learning how to direct his own life and how to manage his attendant. He began receiving attendant services in 1985 as a result of Pennsylvania's pilot program in this area.

The attendant services have changed our family's role from that of David's constant caregivers to mother, father, brother and sister. This service has allowed me the opportunity to go to work for the first time in over 20 years and assist my husband's modest income in supporting our 4 children in college.

I am employed in the rehabilitation technology center at the Rehabilitation Institute of Pittsburgh. I see everyday what can be and is being achieved through technology for people like David and countless others with severe functional limitations with and without mental impairments. Yet how many individuals go without, go begging or are denied accesa to these and other necessary support services because their State has not yet chosen to put in place a service delivery system for all persons with developmental disabilities?

The individuals who fall under the umbrella term "developmentally disabled" are not a homogeneous group in terms of service needs.

I am here today representing over one million individuals who meet the definition of developmental disabilities but whose primary impairment is not a mental one. I call to your attention that the intent of the law is not being met consistently in all

50 States. . . ."*to assist States to (a) assure that persons with developmental disabilities receive* the care, treatment, and other services necessary to enable them to achieve their maximum potential through independence, productivity, and integration into the community . . ." The original intent of Congress in 1963 was to develop services to meet the needs of people with mental retardation. In 1970 and 1975, this intent was extended to people with other disabilities with similar service needs. And in 1978, the language was modified to assure that just persons with the most substantial disabilities received services.

The Federal definition was purely categorical in 1970 (P.L. 91-517) and later evolved to a mixed categorical and functional one in 1975 (P.L. 94-103) which still had a reference to mental retardation . . . "results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons." In 1976, the Secretary of HEW awarded a contract and appointed a task force to study the confusion and different interpretations in operationalizing the mixed definition. The task force recommended a functional approach to the definition—a *non* categorical definition which emphasized the complexity, pervasiveness, and substantiality of the disability condition(s). The proposed definition was included in the 1978 Act (P.L. 95-602) and continues today. The major differences in this definition from the 1975 Act are:

- *No* specific diagnostic categories or labels are used other than "mental and physical impairment";
- The age limit for onset of the disability was raised from 18 to 22; and
- The necessity of a *substantial functional* limitation *in three or more areas* of major life activity.

IMPACT OF CURRENT DEFINITION

The current definition excludes persons with mild disabilities, and, by eliminating categories makes it possible for persons with a wide range of diagnostic labels such as spina bifida, spinal cord injury, muscular dystrophy, multiple sclerosis, cystic fibrosis, Tourette Syndrome, and others to be included in the definition along with many persons from the more traditional diagnostic categories of mental retardation, cerebral palsy, epilepsy, and autism, including many persons with multiple mental and physical impairments. In fact, most prevalence estimates suggest that 1 to 1½ million of the three million people classified as "developmentally disabled" are persons without mental impairments.

Though the disabilities are different, the common elements are that the origin of their disability was in the developmental period, that the individuals will need ongoing—possibly lifelong—support services and that the goal of these services should be to increase independence, productivity, and community integration as stated in the 1984 Act (P.L. 98-527).

The definition adopted nearly 10 years ago has had an impact on States but not nearly what some of us expected. Over 20 States still have a State agency which has an exclusive responsibility to persons with mental retardation.

In 1985, New Jersey was the first and only State to adopt the Federal functional definition in State statute. The remaining States have adopted a variety of mixed categorical and functional definitions, many with a strong mental impairment overlay. In my home State of Pennsylvania our Developmental Disabilities Council has just this year committed some resources over the next 3 years to develop a plan for a coordinated comprehensive service system for *all persons with developmental disabilities*. This decision has come about after 5 years of having a stated goal in the plan with no resources. Currently our single State agency is the Office of Mental Retardation in the Department of Public Welfare.

For more than 80 years, professionals have used an approach that focuses on *individual deficits* as the means of deciding whether a person was eligible for available services. The functional nature of the developmental disabilities definition should force a change in determining eligibility to a focus on the *interaction between a person and his/her environment* rather than focusing on deficits seen to be in the person.

CHANGING SERVICE PATTERNS

Changes in the boundaries of eligibility for services which result from adoption and implementation of the current definition will, in all likelihood, mean that the *"newly eligible" people will require even more varied levels and types of supports.* This means that past patterns of service delivery will not be able to adequately accommodate these differing demands. New service patterns will have to be developed,

some old patterns abandoned, and agencies will of necessity learn to become more flexible in their dealing with individuals receiving services.

For example, in the area of community living, the preferred model of support service for someone with substantial functional limitations without a mental impairment is the person's own home or home with a roommate and a personal attendant hired and managed by the individual rather than *placement* in an "eight-bed" group home or other facility.

In the emerging area of supported employment, ongoing support for persons with developmental disabilities who are not mentally impaired will include a variety of services including transportation, physical, speech, and occupational therapies, medications, and applied technology rather than a job coach.

From these two illustrative examples, I trust you can see that the actual delivery of support services for the divergent population I represent today encompasses the same concepts but far different implementation strategies than for persons with developmental disabilities and mental impairment. This is what we urge you to require the Developmental Disabilities Councils to do more of—to assure the services required to support *all persons with developmental disabilities, regardless of categorical diagnosis,* be planned, demonstrated, and assured throughout the land.

CONCLUSION

We have come a long way, but we believe it is now time to reconcile Federal intent with State policy. As Dr. Elizabeth Boggs, a national expert on developmental disabilities, stated upon New Jersey's adoption of the Federal definition into State statute in 1985, "We have had a non-accessing population of people—specifically, young adults with severe physical disabilities—who have had nowhere to go for assistance in putting it all together. These people *really deserve to have an agency that can work for them . . .*"

I urge you to: (1) reaffirm that State Councils be involved in the system reform necessary within their respective States so that each State adopt the Federal definition in a timely manner and (2) assure that each of the States meet the intent of the law by assigning the most appropriate agencies to be responsible and accountable to provide access to the full range of support services for individuals with developmental disabilities without mental impairments. Until that time, the promise of the Act will remain unfulfilled. Over one million citizens will continue to be more dependent than necessary on our resources and robbed of their human dignity and opportunity to contribute to community life.

Mr. WAXMAN. Mr. Guralnick.

STATEMENT OF MICHAEL GURALNICK

Mr. GURALNICK. Thank you, Mr. Chairman.

I am Michael Guralnick, Director of the Child Development and Mental Retardation Center in Seattle, a University-Affiliated Facility that is a part of the University of Washington. I am also this year's president of the American Association of University-Affiliated programs.

From its inception in the early 1960's, UAF programs have been actively involved in providing interdisciplinary training to prepare professionals for involvement in the field of developmental disabilities, in demonstrating the provision of exemplary services, and in disseminating state-of-the-art knowledge and clinical practice to a substantial number of community professionals, parents and paraprofessionals.

Over the years, this program has developed into a comprehensive network addressing the full spectrum of needs in the field of developmental disabilities.

Although much remains to be accomplished, we believe that our original mandate is, in fact, being fulfilled.

Last year alone, for example, over 7,000 individuals from 56 professional disciplines received interdisciplinary training at UAF's, and over 250,000 professionals, parents and others actively involved

in the field of developmental disabilities participated in short courses, seminars, and other community outreach activities.

In addition, UAF's provided services to over 90,000 clients and their families either directly or through technical assistance to community-based service programs.

This quantitative profile, however, cannot reflect adequately the strong commitment of UAF's and the vast array of programs and activities designed to help insure that developmental disabilities individuals are able to fully participate in all aspects of family and community life.

In fact, we believe that we have complemented effectively the other key components of the Developmental Disabilities Act.

In general, funding for the UAF program has followed the broader pattern of Federal Government support for mental retardation and developmental disabilities training.

In real economic terms, training funds advanced consistently upward every year between 1963 and 1972. Thereafter, training expenditures fell rapidly.

Total training funding for 1985 was only one-fourth of the peak real funding level in 1972; and along with the 1984 figure, it represented the smallest spending commitment for training in 22 years.

In fact, according to funding data published by Dr. David Braddock in a recent study entitled "Federal Spending for Mental Retardation and Developmental Disabilities," the administration is spending—in real terms—$1 million fewer on UAF's today than it did at the inception of the program in 1972. In fiscal year 1972 $4.25 million compared with $3.345 million in adjusted dollars as of fiscal year 1985.

Why are these funding trends significant? What is the importance of having adequately trained personnel to provide basic services to persons with developmental disabilities?

From a policy perspective, the moneys expended on badly needed services are only as effective as the availability of adequately prepared professionals qualified to implement those services.

In order for persons with developmental disabilities to live in community settings, to work in competitive employment environments, and to participate fully in integrated classrooms, it is essential that our case managers, physicians, group home workers, and allied health professionals for example, develop the skills necessary to address the specialized needs of disabled individuals.

The principal impact of these funding reductions is to impair the UAF network's ability to "leverage" other funds. Congress envisioned a unique financing approach in establishing the UAF system. These facilities use their Federal moneys primarily for administrative expenses, but use the all-important Federal commitment to attract funds from State, local, and private sources. The core funds then provide the operational dollars necessary to carry out their training, exemplary service, and other statutory mandates.

However, because the scope of current training needs is growing so rapidly in a variety of areas ranging from health care and case management to vocational service provision, our multi-source budget is barely keeping pace.

In fact, we simply lack the personnel necessary to staff both the training programs themselves and the direct service positions necessary to meet existing requirements in many specific disciplines.

For example, recent surveys have documented the acute shortage of pediatricians especially trained in the field of developmental disabilities.

As a consequence, the highly technical specialized services often required for developmental disabilities children and their families are affected by this shortage of specialists.

Of equal importance is the fact that these same specialists are the ones who provide training for future primary care pediatricians.

Since primary care pediatricians operate as our first line of defense against developmental disabilities, the result is clear. Without the capacity to identify developmental disabilities in our children, we will be unable to furnish appropriate community-based services in a timely, effective fashion.

In our view, the availability of qualified professionals in the generic service system is one key to full participation in community life for developmental disabilities individuals.

As we proceed further in our efforts to enhance the health and general well being of developmental disabilities individuals, we are confronted with a number of serious problems which we believe should be addressed in the Developmental Disabilities Act.

First, the area of elderly developmental disabilities individuals poses significant training and service needs. Current data indicate that there are over 200,000 individuals in this country who are 55 or older with mental retardation or some other form of development disability.

This population is projected to increase to 589,000 by the year 2020. Indeed, this would imply that, as we approach the 21st century, about 4 out of every 1,000 older Americans will have mental retardation or a developmental disability.

Coupled with the aging of parents who have provided life-long care for their sons or daughters with a disability, a major service challenge is upon us.

AAUAP recognizes that one of the first steps in providing the appropriate quality and mix of services to older Americans with disabilities is adequate personnel preparation.

Consequently, we support a cross-training effort whereby UAFs, co-located in the same or adjacent universities with gerontological training programs, provide instruction in the processes of aging and the basic competencies necessary to effectively treat elderly persons with developmental disabilities to a broad array of professionals.

Another area with enormous interdisciplinary training implications involves the recently passed Education of the Handicapped Act Amendments of 1986, P.L. 99-457, which authorized a new early intervention program for disabled children from birth to 3 years of age.

The hearings leading up to the passage of this legislation established beyond reasonable dispute that properly administered early intervention services strengthen prevention, facilitate future com-

munity integration, and actually reduce the severity of a child's functional limitations while enhancing parental involvement.

However, current data reveal a severe lack of qualified personnel in certain key health disciplines including speech pathologists and physical and occupational therapists to meet the expectations embodied in P.L. 99-457.

As a consequence, AAUAP supports a proposal which would augment—via the Developmental Disabilities Act—training dollars provided for under the Education for the Handicapped Act by establishing development and implementation projects at five to seven universities across the country.

UAFs would be specifically responsible for producing a range of allied health professionals from a variety of disciplines to work exclusively in the early intervention programs once they are implemented at the State level.

As the residential services system continues its evolution toward less restrictive, better integrated residential care options, the direct responsibilities given to paraprofessionals to ensure high standards of care and habilitation will also increase.

The proper training of these paraprofessionals constitutes an area of AAUAP concern. The principal difficulty is that we are producing trained direct care staff at a level sufficient neither to meet current demand nor projected needs.

For example, the existing nationwide demand for paraprofessionals—meaning psychiatric technicians, rehabilitation assistants, case workers, house parents, job coaches and group home workers to name a few—is approximately 50,000 for community residential facilities alone.

By the year 2000, that figure increases to over 75,000. Moreover, just to keep pace with the average turnover in these positions between 1987 and the year 2000, 34,000 new paraprofessionals per year will need to be trained.

As a result, AAUAP supports a paraprofessional training initiative in which UAF's would be involved in organizing and preparing existing State and community personnel development programs, assembling and evaluating curricula and quickly disseminating successful training models to community instructional institutions to carry out the actual training.

Finally, UAF supports the creation of a UAF's in every State because the existing feasibility study process is ill-funded, certain States with language populations have no organized Federally sponsored program to provide exemplary services and training in the developmental disabilities field.

UAF therefore proposes that simultaneous expansion studies be conducted leading to establishment of satellite centers in all 50 States by fiscal year 1989.

Thank you for this opportunity to testify in behalf of AAUAP and the UAF's nationwide.

Mr. WAXMAN. Thank you very much, Dr. Guralnick.

[The prepared statement of Dr. Guralnick follows:]

STATEMENT OF MICHAEL GURALNICK

Mr. Chairman and members of the Committee, I am Dr. Michael Guralnick, Director of the Child Development and Mental Retardation Center in Seattle, a Uni-

versity Affiliated Facility (UAF) that is a component of the University of Washington. I am also this year's president of the American Association of University Affiliated Programs (AAUAP).

From its inception, the UAF network has had a unique mission that can be traced back to the early 1960's. The President's Panel on mental Retardation, created in 1961, first initiated the concept of training a multidisciplinary core of professionals required to deliver appropriate and needed services to persons with developmental disabilities. While funds for the construction of research and training centers on university campuses across the country were initially authorized in the Mental Retardation Facilities and Community Mental Health Centers Act of 1963 (P.L. 88-164), the specific statutory mandates for the UAF network were not defined in Federal law until 1978 with the passage of the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments (P.L. 95-602). Sec. 102 of that legislation defined the term "university affiliated facility" as a public or nonprofit facility which is associated with, or is an integral part of, a college or university and which provides for at least the following activities:

(a) Interdisciplinary training for personnel concerned with developmental disabilities;

(b) Demonstration of the provision of exemplary services;

(c) (i) Dissemination of findings relating to the provision of services; and; (ii) providing researchers and government agencies sponsoring service related research with information on the needs for further service related research.

The UAF program has now developed into a comprehensive network emphasizing pre- and in-service training in the field of mental retardation and other developmental disabilities. Last year alone, over 7,000 individuals from 56 professional disciplines received interdisciplinary training at UAF's. Moreover, over 250,000 professionals, parents, and others actively involved in the fields of developmental disabilities participated in short courses, seminars, and other community outreach activities. In addition, UAF's provided essential services to over 90,000 clients and their families. These statistics, however, cannot reflect adequately the strong commitment of UAF's and the vast array of programs and activities designed to help ensure that developmentally disabled individuals are able to fully participate in all aspects of family and community life. The scope of our activities continues to be extensive, encompassing areas such as prevention, early intervention, transition, employment, mental health problems of disabled individuals, community living arrangements, and the coordination of services. As partners in the developmental disabilities program, we believe that we have complemented effectively other key aspects of the Developmental Disabilities Act.

In general, funding for the UAF program has followed the broader pattern of Federal Government support for mental retardation and developmental disabilities training. In real economic terms, training funds advanced consistently upward every year between 1963 and 1972. Thereafter, training expenditures fell rapidly. Total training funding for 1985 was only ¼ of the peak real funding level in 1972; and, along with the 1984 figure, it represented the smallest spending commitment for training in 22 years. In fact, according to funding data published by Dr. David Braddock in a recent study entitled, "Federal Spending for Mental Retardation and Developmental Disabilities," the Administration is spending—in real terms—one million fewer dollars on UAF's today than it did at the inception of the program in 1972 ($4.25 million in FY 1972 compared with $3.345 million in adjusted dollars as of FY 1985).

Why are these funding trends significant? What is the importance of having adequately trained personnel provide basic services to persons with developmental disabilities? From a policy perspective, the moneys expended on badly needed services are only as effective as the availability of adequately prepared professionals qualified to implement them. In order for persons with developmental disabilities to live in community settings, to work in competitive employment environments, and to participate fully in integrated classrooms, it is essential that our educators, physicians, group home workers, and allied health professionals develop the skills necessary to address the specialized needs of these individuals. The interdisciplinary training approach, in particular, plays a key role in the personnel development process. Pediatricians and other physicians, occupational and physical therapists, speech pathologists and other allied health professionals are trained to function as a team in dealing with the complex needs of an individual with developmental disabilities in a unified manner. Because these needs require responses from many agencies and many types of professionals, this interdisciplinary training approach is designed to result in coordinated, appropriate service provision.

Viewed in this light, it seems clear that decreasing support for the UAF system and other personnel development programs will inevitably compromise the availability and quality of health care and other services to persons with developmental disabilities. The principal impact of this reduction is to impair the UAF network's ability to "leverage" other funds. Congress envisioned a unique financing approach in establishing the UAF system. These facilities use their Federal moneys primarily for administrative expenses, but use the all-important Federal commitment to attract funds from State, local, and private sources. The leveraged funds then provide the operational dollars necessary to carry out their training and exemplary service statutory mandates. In fact, while ADD funded UAF's received $7,653,000 in core funding during FY 1986, these same programs generated $45,211,000 from Federal sources including the Division of Maternal and Child Health, the Department of Education, and the National Institutes of health. Yet all Federal funding accounted for just over 25 percent of the total UAF income. The Administration on Developmental Disabilities' investment of $7,653,000 resulted in a total income of $122,000,000 nationwide or a ratio of $16 generated for every $1 Federal dollar invested. The largest sources of other funds include general university revenues as well as State and local support taking the form of grants or contracts from governmental entities and community-based private nonprofit organizations.

However, because the scope of current training needs is growing so rapidly in a variety of areas ranging from health care and case management to vocational service provision, our multisource budget is barely keeping pace. In fact, we simply lack the personnel necessary to staff both the training programs themselves and the direct service positions necessary to meet existing requirements in many specific disciplines. For example, recent surveys have documented the acute shortage of pediatricians specially trained in the field of developmental disabilities. As a consequence, the highly technical specialized services often required for developmentally disabled children and their families are affected by this shortage of specialists. In addition, these same specialists are the ones who provide training for future primary care pediatricians. Since primary care pediatricians operate as our first line of defense against developmental disabilities, the result is clear. Without the capacity to identify developmental disorders in our children, we will be unable to furnish appropriate services in a timely, effective fashion. The availability of qualified professionals in the generic service system is one key to full participation in community life for developmentally disabled individuals.

In addition to the sheer scope of the nationwide personnel development need, the internal financing dynamics of the UAF system are impacting our capacity to fulfill the statutory mandates outlined in the Developmental Disabilities Act. Because basic Federal support has eroded over the past decade, those dollars are making up an increasingly smaller share of the overall network budget. As a result, it is now more difficult to maintain the developmental disabilities focus of these programs while attracting the funds necessary to carry out the mandated training and exemplary service functions. Specifically, becausse our Federal funding is now proportionately less significant, the national network is increasingly subject to the influence of non-developmental disability training and service priorities.

It is crucial to emphasize, therefore, that the Federal commitment establishes the broader programmatic structure for the network. Core funding provides the critical mission for the disparate resources gathered by UAF's. Without the funds that bind the program together, the developmental disabilities focus of these facilities may be lost or compromised. The presence of Developmental Disabilities Act funding provides the central mechanism, within sometimes vast university educational systems, to coordinate moneys from many different sources towards a set of established objectives. As a consequence of reduced Federal involvement, many of the activities currently pursued by UAF's, including exemplary services, technical assistance activities to community agencies, and much of the existing outreach program would be seriously jeopardized.

Before moving on to a discussion of specific training and service issues, I would like to make a brief comment about the Developmental Disabilities Act in general. Despite relatively modest funding, the ideals and programs embodied in the Act have had an enormous impact on the field as a whole. The relatively small authorization increases now proposed by the Consortium for Citizens with Developmental Disabilities (CCDD) continue this evolutionary process by, for example, furthering the role of Developmental Disabilities Councils in building the capacity of the public and private sectors—at the State level—to provide services to people with developmental disabilities. The Protection and Advocacy system would be authorized to represent individuals who, for example, without the protection of a family or legal guardian, are often summarily relocated from State institutions to sometimes inap-

propriate living arrangements. Moreover, these authorization levels also give UAF's the capacity to effectively address some of the broader issues that will soon dominate the developmental disabilities landscape. These issues involving areas of aging, early intervention, paraprofessionals, and expansion are discussed below.

AGING

Current data indicate that there are over 200,000 individuals in this country who are 55 or older with mental retardation or some other form of developmental disability. This population is projected to increase to 589,000 by the year 2020. This would imply that, as we approach the 21st Century, about 4 out of every 1,000 older Americans will have mental retardation or a developmental disability.

These figures also suggest that, as a Nation, we will soon be faced with the aging of parents who have provided life-long care for their sons or daughters with a disability. As these elderly parents become incapable of providing care, States and communities are increasingly confronted with the task of finding appropriate community-based placement. Yet even the current population, often housed in nursing homes and community residential facilities, receive inadequate or inappropriate care from ill-trained staff.

AAUAP recognizes that one of the first steps in providing the appropriate quality and mix of services to older Americans with disabilities is adequate personnel preparation. Consequently, we support a cross-training effort whereby UAF's, co-located in the same or adjacent universities with gerontological training programs, provide instruction in the processes of aging and the basic competencies necessary to effectively treat elderly persons with developmental disabilities. Such training would be provided to a broad array of professionals including social workers, physicians, occupational and physical therapists, psychologists, audiologists, speech pathologists, and nutritionists.

EARLY INTERVENTION

Another area with enormous interdisciplinary training implications involves the recently passed Education of the handicapped Act Amendments of 1986 (P.L. 99-457), which authorized a new early intervention program for disabled children from birth to 3 years of age. It is designed to assist States in developing and implementing a statewide comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for handicapped infants and toddlers and their families. The program mandates the provision of family training and counselling, case management services, physical and occupational therapy, and assessment services among many others. The hearings leading up to the passage of this legislation established beyond reasonable dispute that properly administered early intervention services strengthen prevention, facilitate future community integration, and actually reduce the severity of a child's functional limitations while enhancing parental involvement.

However, current data reveal a severe lack of qualified personnel in certain key disciplines to meet the expectations embodied in the EHA. As an example, of the 44,000 members of the American Occupational Therapy Association, approximately 53 percent either work with children exclusively or serve both children and adults. While this figure represents a dramatic increase in the number of occupational therapy personnel engaged in pediatric practice, it is clear that the majority of pediatric therapists are treating children ages 5 through 18 years of age. In fact, less than 2 percent of occupational therapists work primarily with children during the first year of life. In addition, it is alarming to note that similar personnel shortages are shared by the other critical allied health disciplines. A recent survey of the 50 States indicates that 96.2 percent report substantial shortages of qualified physical therapists, speech pathologists, and occupational therapists to work in the early intervention program. In addition, 82.7 percent of these States expect the shortage to continue through 1989, the first year of implementation of P.L. 99-457.

These disturbing numbers reflect why AAUAP supports a proposal which would augment—via the Developmental Disabilities Act—training dollars provided for under the EHA by establishing development and implementation specifically responsible for producing a range of allied health professionals from a variety of disciplines to work exclusively in the early intervention programs once they are implemented at the State level.

PARAPROFESSIONALS

The AAUAP network has long advocated for the community integration of persons with developmental disabilities. The enhanced health and developmental progress of individuals who reside in natural communities and relatively normal, household size living arrangements (rather than specialized institutional environments) have been amply demonstrated. A consequence of this approach is that persons with developmental disabilities increasingly live, work, and recreate outside of environments with formally trained professionals. Indeed, as the residential services system continues its evolution toward less restrictive, better integrated residential care options, the direct responsibilities given to paraprofessionals to ensure high standards of care and habilitation will also increase. The principal difficulty, however, is that we are producing trained direct care staff at a level sufficient neither to meet current demand nor projected needs. For example, the existing nationwide demand for paraprofessionals—meaning psychiatric technicians, rehabilitation assistants, case-workers, house parents, job coaches and group home workers to name a few—is approximately 50,000 for community residential facilities alone. By the year 2000 that figure increases to over 75,000. Moreover, just to keep pace with the average turnover in these positions between 1987 and the year 2000, 34,000 new paraprofessionals per year will need to be trained.

Clearly these estimates suggest that the lack of appropriate personnel development could become a substantial roadblock to community integration of persons with developmental disabilities. As a result, AAUAP supports a paraprofessional training initiative whereby UAF's would administer 5 to 10 training programs for direct care workers and paraprofessionals. With the overall objective of organizing and preparing existing State and community personnel development programs, curricula would be assembled, evaluated, and quickly disseminated to community instructional institutions to carry out the actual training. In view of the substantial task ahead, this recommendation represents an immediate and cost-effective method of building training capacity at the local level.

EXPANSION

Finally, AAUAP supports the creation of a UAF in every State. Because the existing feasibility study process is ill-funded, certain States with large populations—like Illinois—and a substantial portion of the south and southwest area—including Oklahoma, Arkansas and New Mexico—have no organized federally sponsored program to provide exemplary services and training in the developmental disabilities field to allied health professionals, parents, and physicians already in the field. AAUAP, therefore, proposes the conduct of simultaneous expansion studies leading to the establishment of satellite centers in all 50 States by FY 1989.

Thank you for this opportunity to testify on behalf of AAUAP and UAF's nationwide.

STATEMENT OF CATHERINE A. RAGGIO

Ms. RAGGIO. I am Catherine A. Raggio, executive director of the Maryland Developmental Disabilities Council and today I represent the 56 State and territorial council on behalf of the National Association of DD Councils.

I come from the State where once an illustrious congresswoman followed your leadership. We were sorry to lose her from this committee but of course delighted by her new role in the center and are very assured to know that your leadership continues.

The DD Council recommendations concerning reauthorization of the Act have been incorporated into those made by the consortium for citizens with DD, also known as CCDD. Copies are attached to my testimony and I want to highlight some key recommendations and present some strengths of the DD program.

Through the basic State grant program councils work to build the capacity of services within their States. Our funds are used as a catalyst for State, local and other Federal and private dollars.

For example, 2 years ago, in Maryland, my council members volunteered me to be a chair of an interagency grant writing that captured one of the original 10 grants from the Office of Special Education and Rehabilitation services. This grant is being used to convert Maryland's way of serving people with DD from workshops and activity centers to supported employment.

Not only did Maryland receive the $2.1 million over a 5-year period in Federal funds but we also have received to date $97,000 for the program from private foundations.

State resources in excess of $10 million over the 5-year period will be redirected to supported employment which we believe to be a new and better way to serve people with DD.

Ours is a people program. Although we do not usually provide direct services unless for demonstration purposes we use our small allocations to leverage long-term funding and to promote long-term funding and to promote more efficient uses of State and local resources. Councils must frequently identify their State legislative outcomes as their most significant achievement. In each State, councils act as educators, influencing and leveraging agencies according to their own circumstance.

Attached to my testimony is the National Association of DD Council publication titled "Patterns for Advocacy," which describes policy activity for fiscal year 1985. The fiscal year 1986 document will be available soon and will be forwarded to members of the subcommittee. As planners and advocates, councils must promote ideas and service approaches on the cutting edge.

We spend considerable time discussing our beliefs and philosophies and one of our beliefs is the people with DD are people first and that services must reflect the person's own opinion and their choices.

The Minnesota Council has prepared this book entitled "New Way of Thinking," to help policy makers and the public understand the issues surrounding the lives of people with DD and our society's responsibility to them and a copy of that is attached.

Many councils have been helping people with DD to speak for themselves through self-advocacy training programs. The Maryland Council has just published this guide called "You Can Do It," which is a guide to services in Maryland for young adults with DD and it encourages individuals to take charge of their lives.

Language makes a big difference in communicating our attitudes towards and our vision for people with DD. To address the question of values the CCDD has recommended language changes which reflect the dignity of the individual and they also recommend adding to the purposes of the act consumer and family empowerment and we wholeheartedly agree.

One of the most important council roles has been in its activities to promote policy change. Such activities take many forms including educating policy makers, building coalitions and building interagency cooperation. We support the CCDD recommendations that will enhance the council's ability to advocate for policy change at the State level.

The 1984 reauthorization began the process to encourage councils to look critically at their State institutions. Beginning in 1988 we would like the councils to report to their governors and to the ad-

ministration on State responsibilities and plans to correct deficiencies.

Council action is needed to underscore our values of independence, integration and productivity and to prevent costly impediments to institutions.

We also advocate for flexibility in the DD Act. The four priorities for council work have always allowed the councils to be future thinking and at this time we support CCDD recommendations that councils be able to select the number and type of Federal priorities appropriate within our States.

We also support the reinstatement of the State option when the councils work over-arches two priorities or in the case of consumer empowerment activity when it extends beyond the four priorities.

We also need your support of the CCDD recommendations that will enhance the autonomy of the councils. It is a most difficult job to advocate within State government and we rely heavily on the DD Act to support our autonomy.

We also support the CCDD recommendations fostering the work of the protection and advocacy programs, and university affiliated programs. These organizations help the councils to accomplish the goals and objectives in the State plan.

The basic State grant program takes pride in its smallness and councils have demonstrated through their credible policy analysis public education and the seeding of larger initiatives that many more services have been created for people with DD on the State level than could ever have been expected from the financing under the DD Act alone.

The program has been losing ground steadily though since 1975. In fact, since that time the budgetary growth of this program averaged only 6 percent a year in unadjusted dollars. In real economic terms the funding actually regressed by 30 percent which is a very bleak economic picture.

We will forward to the subcommittee charts developed by Dr. Davis Braddock of the University of Illinois at Chicago depicting this loss of buying power. Therefore councils are recommending appropriations for the basic State grant program at $62.2 million for fiscal year 1988, a 10 percent increase.

Councils have been self-critical and have constantly sought to improve our effectiveness as advocates. We are fortunate that our councils must contain a majority of people with DD and parents since they are indeed the conscious of the council. Having the opportunity to give Congress the benefit of our best thinking every 3 years during the reauthorization process allows us to contribute to the strengthening of the DD Act and therefore to our own effectiveness and improving the lives of citizens with DD.

We appreciate being able to appear before the House Subcommittee on Health to make our recommendations to you.

Thank you.

[Testimony resumes on p. 81.]

[Ms. Raggio's prepared statement follows:]

THE NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES COUNCILS

Good morning. My name is Catherine Raggio. I'm the Executive Director of the Maryland Developmental Disabilities Council and I am representing the 56 state and territorial DD Councils on behalf of the National Association of Developmental Disabilities Councils (NADDC). I am a member of NADDC's Board of Directors, representing the four mid-Atlantic states and the District of Columbia.

The specific recommendations made by DD Councils regarding the reauthorization of the Developmental Disabilities Act have been incorporated into those made by the Consortium for Citizens with Developmental Disabilities(CCDD), copies of which are attached to my testimony. I would like to highlight a few of the most critical recommendations and to present what I think are the strengths and possibilities of the DD Basic State Grant Program.

WHAT DEVELOPMENTAL DISABILITIES COUNCILS DO

The DD Basic State Grant Program provides modest allocations to states and territories for activities which build the capacity of the public and private sectors to provide services and other support to people with developmental disabilities and their families. These funds act as catalysts for state, local, and sometimes federal public and private dollars. It is the responsibility of the DD Council to be the state-wide planner and advocate for people with developmental disabilities. DD Council advocacy takes many forms. Councils help to coordinate and influence state agency activities by combining resources to meet the needs of people with developmental disabilities and by providing funds to train agency personnel needed to realign services to fill

service gaps. Councils advocate for increased state funding for state agency budgets for particular services. Councils organize and participate in coalitions to mobilize efforts to educate state policy-makers to the need for and benefits of particular services for people with developmental disabilities. Council activities rearrange service configurations and change the direction of services for new and better use of federal programs on behalf of people with developmental disabilities. Councils educate and raise the awareness of the general public about the nature of developmental disabilities to reduce prejudice and fear associated with community integration.

Ours is a "people" program that does not provide direct services to people; rather we use our small allocations to leverage long-term funding and more efficient use of resources to fill gaps in and improve the system. It is a time of scarcity in most states and Councils must anticipate future trends in order to plan and advocate most effectively. Of the approximately 16 billion dollars spent on services and entitlements to people with developmental disabilities nationally, the DD program represents only $56.5 million - about one-third of one percent. And yet this dollop of money is a magnet for other funds, a motivator for the realignment of services and a supporter of advocacy resulting in new and better services.

Because of the unique composition of DD Councils, all the key actors in the state design the strategies to be used to meet Council goals. People who need services, state and local providers of services, and state movers and shakers sit together at the Council table to plan, advocate and help shape state policy to improve the quality of life for people with developmental disabilities and their families.

The change agent role given to DD Councils in the Developmental Disabilities Act to shape state disability policy is the critical component in fostering "independence, productivity and integration into the community for people with developmental disabilities." This mission requires multi-faceted approaches to working with the varying state systems which reflect differences in political, economic and social environments. A variety of strategies are used by Councils to achieve this mission. Councils must assess the system as it currently exists, determine how it can be improved, plan policy goals and objectives and take a leadership role in achieving the policy changes that can create those improvements. Councils act as educators, influencers and leavening agents in their own unique set of circumstances. Councils initiate or modify state laws pertaining to services or rights as a critical strategy to improve the lives of people with developmental disabilities. Attached to my testimony is an NADDC publication, "Patterns for Advocacy: How Councils on Developmental Disabilities Achieve Public Policy Goals", which describes DD Council policy activities for fiscal year 1985. A FY 1986 document will be available soon and forwarded to members of the Subcommittee.

Several aspects of the Council role are important to underscore. Councils exist because Congress has determined that change is needed. We would like to describe Councils' visions for change predicated upon positive values, how they identify and plan to nurture the highest quality services, and how Council advocacy alters public policy. Integral to this planning and advocacy are some critical administrative questions which we shall also address.

BEST PRACTICES ROOTED IN OUR VALUES

The DD Council, in its role as planner and advocate, has the position, authority and responsibility to identify and promote those ideas which are on the cutting edge of services for people with developmental disabilities. To see that federal funds are used appropriately, that the needs of people are met by the states, and that services that meet those needs promote independence, productivity and integration into the community, Councils must be aware and make others aware of new ways of thinking and acting. Councils approach the question of values in many ways.

The Minnesota Council has prepared the booklet, "A New Way of Thinking," to help policy makers and the public understand the issues surrounding the lives of people with developmental disabilities and our society's response to them. A copy of that publication accompanies my testimony. Such public education, coupled with other policy analysis, training and demonstration of ways to implement new ideas, help Councils achieve their long-range objectives to assure a service system which promotes independence, productivity and integration into the community.

Councils such as those in Connecticut, Wisconsin, Pennsylvania and Michigan have sponsored Program Analysis of Service Systems (PASS) training, recognized as the leading approach to train professionals, advocates, providers and consumers in the values upon which services should be based and how those values can be put into everyday practice. Simply put, those values are that each person must be viewed first as a human being rather than a "client" or a "disabled person" and that any intervention in a person's life should reflect

that respect and the individual's own opinions, desires and aspirations. These values are part and parcel of any new way of thinking about "independence, productivity and integration into the community." How do these values translate to the purposes of the DD Act?

Independence means that people should make decisions about their own lives with the support necessary to inform those decisions. It means that people must have freedom of choice about where and with whom they live and have the right to take risks to explore life and its possibilities. Independence also implies interdependence: each of us needs others in our lives for friendship and support.

Productivity addresses this need to make a contribution to society and to use all the talents an individual has. For adults it means meaningful work that is valued by others. For children, it means the opportunity to learn how to be productive.

Integration into the community means being with all kinds of other people, living in a real home and having neighborhood and other social experiences. It also means being accepted by others as a potential friend.

Self-advocacy is a term used to describe the manner in which people speak for themselves in getting their needs met, whether it means standing up for the type of service you want to get a job or facing the ordinary negotiations between tenant and landlord. Several Councils, including Wisconsin, Maryland, Oregon, and Kentucky, have supported programs which train consumers, provide peer support and regenerate the ideals and values of the DD Act by enhancing

the independence of individuals with developmental disabilities. Parents, too, are provided support and training such as the Utah Council's program to help parents plan the future vocational development of their children. Maryland concentrated on assisting young adults to develop self-reliance and clarity of purpose during the teenage years.

Connecticut has focused on the community at large, helping various segments to understand and meet the needs of people with developmental disabilities by training police, judges, lawyers, public defenders, bus drivers, landlords, apartment superintendents, barbers and many others. This will have a two-fold effect of decreasing discrimination and increasing acceptance, and building understanding of public policy goals around the needs of people with developmental disabilities.

Language makes a difference in communicating our attitudes toward and our vision for people with developmental disabilities. To address the question of values, the CCDD has recommended language changes which reflect the dignity of the individual and recommends adding to the purposes of the Act, consumer and family empowerment. DD Councils wholeheartedly agree.

All of these and many other examples show how Councils promote new service responses and support a positive context for acceptance of people with developmental disabilities in society.

ANTICIPATING THE FUTURE

DD Councils are designated as planners as well as advocates. Based on our values, DD Councils have to have accurate crystal balls to be able to spot future trends, to recognize state-of-the-art services when we see them and to know when and how to push them. However, DD Councils must also be practical about the methods developed to meet needs of people while expressing those values. If we hold a value that all children should grow up with families who love them, then we must determine ways to accomplish that. Several Councils, including Wisconsin, Colorado, Ohio, North Carolina and others, have influenced the establishment of locally financed family support programs which provide subsidies and direct supports to families who are caring for children with intense and special needs. Councils have done research on model programs, funded demonstrations of family support and then worked within state government to ensure the establishment and funding of family support programs. Respite care is another innovation which Councils, including those in Massachusetts and New Jersey, have helped to make a part of the ongoing service system. These services shore up the natural supports available to people with developmental disabilities so that they can live and function as other people do, at home.

Community living has always been a major goal of the Councils since the Congress found in 1970 that "it is in the national interest to strengthen specific programs, especially programs that reduce or eliminate the need for institutional care." Councils have been in the vanguard of efforts to move states away from policies which perpetuate congregate care facilities, as, for example, the advocacy of the Hawaii Council in gaining the state legislature's

support for a planned reduction and eventual closure of that state's sole institution. Councils also have worked to establish new living situations for people with developmental disabilities by promoting ideas such as supervised apartment living in Utah, shelter homes in Idaho, appropriate zoning in Illinois, adoption for special needs children in the District of Columbia, better guardianship laws in North Dakota, consumer-owned cooperative housing in New Hampshire--all ideas which help assure that people live in homes, not just in buildings.

As part of their function to monitor federal programs to promote independence, productivity and integration, Councils have advocated for the use of the Medicaid Home and Community Based Waiver, providing policy support to encourage and formulate applications, technical assistance to community providers responsible for the waivered services, and evaluating the implementation of the waiver. California's Council pioneered that state's efforts to use the Medicaid program for people, including infants and children, with intensive medical needs, promoting programs that provided a truly homelike setting in which the individual's needs could be met. Many Councils, prior to and since the mandate to address employment, have worked successfully with state vocational rehabilitation agencies, which receive funds under the federal Vocational Rehabilitation Act. Pennsylvania, Michigan and Indiana have been among those promoting the inclusion of supported employment and other new, innovative ways to encourage appropriate training and real jobs for people with developmental disabilities. Councils are involved with these and other federally supported programs by virtue of the authority given in the Developmental Disabilities Act to "review and comment" on the plans for these programs. The recommendation of the CCDD to include

the plan for federal aging services under this Council responsibility appropriately moves into an area which is receiving much attention in the field, the growing population of older persons with developmental disabilities.

Councils are increasingly supporting the development and use of new methodologies which meet the needs of people with developmental disabilities. These can include implementing scientific discoveries about what methods help people learn and disseminating information about new equipment or computer capabilities. Texas and Minnesota have developed ways to increase the use of innovative equipment and scientific technologies, such as communication devices. The CCDD recommendation to define and include applied technology in the definitions of community living and employment affords recognition of this critical and potentially revolutionary approach to supporting individual independence.

THE IMPORTANCE OF POLICY CHANGE ACTIVITIES

Once values are clarified, problems identified, and solutions planned, it remains to educate and influence the people and systems responsible. Legislators are critical decisionmakers and Councils have been successful in educating them and the public about values, problems and solutions. Education that results in change must be based on fact and substance. Councils have conducted much research which has been essential to legislative and other policy changes. Councils are particularly proud of this aspect of their work and most frequently identify new legislation as their most significant accomplishment. The California Council sponsored and gained passage of legislation which increased the scope and budget for the Birth Defects Monitoring Program and gained commitment for future program expansion. Their prior research efforts gave the credibility this initiative needed in order to gain the support of policy makers. The Illinois DD Council was asked by the state legislature to conduct three major policy analyses on housing needs, abuse and neglect of adults, and the transition of children to adult services. These three studies will provide the direction for the state's future policy activities in these areas. The Minnesota DD Council has taken a lead in policy analysis which results not only in changes in state policy, but in broad-based attitudinal change among the general public. That Council has provided research at the request of the Governor. In conjunction with other organizations and advocates, the Iowa DD Council achieved passage of a Bill of Rights for people with mental retardation, developmental disabilities and chronic mental illness. The Council promotes public and consumer awareness of the law and is monitoring its implementation.

Another critical area in support of the mission of DD Councils is the

promotion of citizen awareness and action through coalition activities. By helping to build alliances, improving coordination and communication, a united front among disability and other organizations can be accomplished, a critical ingredient for successful advocacy over a long period of time and in a large number of issue areas. DD Councils have founded and organized coalitions and continuously participate in coalition advocacy with many groups. Legislative results range from the passage of seat belt laws to prevent disabling injuries to blocking cutbacks in state general funds for community services and to generating millions of state dollars for early identification and intervention services.

In the executive branch of state government, there are many resources which can assist people with developmental disabilities if those resources are properly influenced and choreographed. DD Councils have been the catalysts for interagency cooperation on the state level by creating the forum within which dialogue can take place and by providing funds which leverage state and local agency funds. The Maryland DD Council, for example, as part of its larger effort to address the lack of services for adults with developmental disabilities, focused on local agency collaboration to implement supported employment programs by using Council funds to establish linkages between experienced and beginning agencies for training and technical assistance. The New York DD Council spurred interagency efforts with the state aging agency to develop services to elderly people with developmental disabilities. Indiana pooled its own funds with funds from vocational rehabilitation, the Job Training and Partnership Act program, and other related programs to sponsor supported employment.

The CCDD recommends strengthening the policy role of the DD Council by including in the list of activities in support of the priority areas policy analysis and educating policy makers. These activities provide critical support to demonstrate the need for change and are the underpinnings of credible DD Council advocacy. DD Councils strongly support this recommendation since these activities are central to the continuing effectiveness of the DD Basic State Grant program.

DD Councils also support another CCDD recommendation which will improve our ability to effectively advocate for policy change at the state and local levels. The 1984 reauthorization began a process to involve DD Councils in policy planning when states were cited with deficiencies in their ICF/MRDD facilities. Beginning in 1988 we would like Councils, in their Annual Report to the Administration and to their Governor, to report on the state response to these deficiencies and to describe Council actions which support independence, productivity and community integration for people with developmental disabilities as opposed to continued institutionalization in facilities which do not meet federal standards. Council action is needed to prevent costly improvements to institutions at the expense of community services.

UNIQUENESS OF STATE NEEDS REQUIRES FLEXIBILITY IN THE DD ACT

All of these accomplishments are not single results of single actions; concerted efforts in many arenas are neccessary to achieve such goals. Research must be done to develop new strategies and technologies of providing services. Analyses must be conducted to support policy changes. Demonstrations must be made of new methods. Advocacy and public understanding must be supported to assure the empowerment and acceptance of people with developmental disabilities in the community. Councils act on all these fronts.

As the CCDD recommends, Councils need to be able to select the number and type of federal priority areas they deem necessary and appropriate to meet the needs of people with developmental disabilities in the individual states and territories in their uniqueness. The option must also be available to Councils to choose a course of action which overarches the federal priorities or which goes beyond what might be included in the four federal priorities. Under the previous "state option" in the DD Act, Councils have been successful in using their federal funds to address special problems, such as the needs arising out of the rural character of Montana or the complexity of addressing local variations in services through the regional DD Councils in Missouri and area boards in California. These two recomendations will assist the Councils to meet the needs they identify at the community level.

This flexibility should also extend to how and where the Basic State Grant program is administered. The CCDD recommends that each Council be allowed to be designated its own state administering agency and that the Council's authority over use of the funds be enhanced. The designation of a Council's

administering agency has been addressed in many different ways in the states and territories. In South Carolina, the Council is in the governor's office; in Minnesota, in the general State Planning agency; Texas is in the vocational rehabilitation agency; Wisconsin is in an umbrella social service agency while a majority of Councils are located in the mental retardation/developmental disabilities services agency. Although some Councils have experienced difficulties in finding the best location to be effective, others have developed satisfactory working relationships with their agencies and have appropriate and sufficient staff to effect the Council's program. The two CCDD recommendations regarding administration would help those states which seek to improve their current situations while continuing to support the Councils and agencies which work well and efficiently together.

SUPPORTING OUR SISTER PROGRAMS

The DD Act created a triumvirate at the state level - DD Councils, Protection and Advocacy Systems (P&As) and University Affiliated Programs (UAPs) - each of which has a special role to play in creating, expanding, monitoring and advocating for services to people with developmental disabilities. To involve P&As and UAPs in the implementation of the DD State Plan, Councils have funded our sister programs to accomplish specific objectives that are part of the state-wide picture. In FY 1985, 17 DD Councils provided funding totalling $1,013,970 to Protection and Advocacy Systems for activities such as: the development of an information collection and storage system for DD-related agencies (Northern Mariana Islands); individual advocacy for people in rural areas (Arizona); training for volunteers to advocate for people leaving institutions (Connecticut); case management for home-bound people (D.C.); a conference on consumer self-advocacy (Kentucky); the development of an outreach/educational forum for parents and consumers on rights (Louisiana); training in citizen advocacy (Montana); training for volunteer advocates for adults and children (Nebraska); training in legislative advocacy skills to parents (New Mexico); support for the development of a P&A in a rural area (Utah); the computerization of P&A information and referral services (Virginia); and citizen advocacy for residents of nursing homes (Wisconsin). The FY 1986 data are still being compiled, but of 36 Councils reporting thus far, 9 indicate that they provided funding in FY 1986 to P&As totalling $783,971 in areas such as: community training regarding civil rights (Oregon); PASS training (Michigan); volunteer training to support families with mentally ill-developmentally disabled members (Nebraska); citizen advocacy training (Montana); advocacy for institutionalized individuals

(Wisconsin and Arkansas); information and referral system (New Mexico); quality assurance activities (Louisiana); a report on the status of DD offenders and a publication of rights under PL 94-142 (Maryland).

In FY 1985, 20 DD Councils provided $1,978,581 to University Affiliated Programs for activities such as: the translation of materials on PL 94-142 (Education for All Handicapped Children Act) into the Navajo language (Arizona); the training of generic community service providers about developmental disabilities (Connecticut); provision of training in the use of technology (Maryland); training, monitoring and evaluation of supported employment (Pennsylvania); and the development of a protocol for drug therapy (Washington). In FY 1986, data from 36 Councils indicate that 23 Councils have provided funds to UAPs totalling $1,746,275 to accomplish the following DD state plan objectives: training for day activity staff, training and resources on autism, epilepsy and cerebral palsy, and evaluation of social/recreational models (Michigan); training for generic service providers (Connecticut); continuing education in prevention in rural areas (Ohio); public policy development for people with developmental disabilities who are not mentally retarded (New Jersey); pediatric AIDS and high-risk intervention services (Florida); travel to visit state-of-the-art residential programs (Colorado); model behavior management methods (Washington); improving inter-disciplinary assessment services (Kentucky); coordination of case management services (South Carolina); project for visually impaired preschoolers (North Carolina); policy research on aging people with developmental disabilities (Massachusetts); training in early intervention for community health nurses (Nebraska); training for Board members of non-profit organizations, recreation research and non-aversive training techniques (Montana); development of a preschool mainstreaming model (Louisiana); and the development of model family support services (Maryland).

DD Councils support the recommendations made by the Consortium for Citizens with Developmental Disabilities (CCDD) regarding the Protection and Advocacy Systems and the University Affiliated Programs.

A WORD ABOUT SPECIAL PROJECTS

FY 1986 marked the first year that the Office of Human Development Services encouraged the participation of DD Councils in the special projects grants by specifying Council eligibility to apply for funds in the employment area. These grants were coordinated with funds from the Office of Special Education and Rehabilitative Services to develop model supported employment activities. Not only was it helpful to have policy planning funds at the state level, but this approach is the model for mandating federal interagency initiatives which encourage policy change at the state level for people with developmental disabilities, which is the CCDD recommendation.

In the 1970's, when special projects funding was ten times greater than it is today, technical assistance was available across the country to assist DD Councils in learning from one another, in sharing best practices and in implementing new amendments to the Act. As funding dropped dramatically, ongoing technical assistance was one of the first things to be eliminated. Training and technical assistance must be reinstated for Councils as well as for the other DD program components, and funds need to be earmarked for this purpose.

The CCDD recommendations regarding changes in special projects are wholeheartedly endorsed by DD Councils who feel that our federal agency, the Administration on Developmental Disabilities, should be in the business of creating and leveraging policy change at the federal level, as DD Councils are at the state level.

MONEY CAN'T BUY RESULTS BUT IT HELPS

The DD Basic State Grant Program is probably one of the only human services programs to take pride in its smallness. (A Congressional staff member recently referred affectionately to the DD programs as "decimal dust.") Councils have demonstrated that through credible policy analysis, public education and the seeding of larger initiatives, many more services have been created for people with developmental disabilities on the state level than could ever have been expected from financing under the DD Act alone. While our smallness has had a large impact, the program has been losing ground steadily since FY 1973. In fact, since that time, the budgetary growth of this program averaged only 6% per annum in unadjusted dollars; in real economic terms, funding actually regressed by 30% - a very bleak economic picture. Therefore DD Councils are recommending appropriations for the Basic State Grant Program at $62.2 million for fiscal year 1988.

Two other resource issues affect the 16 minimum allocation states and territories. We request that the minimum allocation be raised to $350,000 for the states and District of Columbia and to $200,000 for the territories and that the Administration on Developmental Disabilities increase the minimum allocations administratively in those years in which appropriations are greater than the Consumer Price Index rate of increase.

In a third area, resource administration, another change is needed. DD Councils provide 65% of their priority area funds to public and private agencies and organizations which perform activities supporting state plan objectives. From time to time, these subgrantees will return unexpended funds

in the next fiscal year which the Council then cannot reobligate. We recommend that an allowance of 10% of the annual allotment be permitted to be carried over for this type of contingency and that funds obligated in the current fiscal year but returned in the next fiscal year be available for reobligation according to State Plan priorities.

Finally, regarding funding for the programs authorized by the DD Act, the attached analysis by Dr. David Braddock of the University of Illinois at Chicago has shown a dramatic plunge in the buying power of UAF, DD Council and Special Projects dollars. In addition, these DD programs have been particularly hard hit by the effects of inflation and the increased cost of services by level funding in the years since 1981. Therefore, DD Councils support the authorization of appropriations for the three-year period for the four DD programs recommended by the CCDD.

CONCLUSION

If money alone were power, then the DD program would be powerless, given its modest financing. Credibility and influence are the critical ingredients. To be credible and influential -- to do what we are mandated by Congress to do -- means that our judgment about what needs to be done must be highly honed, each investment we make must be attached to a concept we have confidence in, and our word must be trusted based on our successful track record and the quality of our knowledge. To foster and enhance the credibility and influence of every state and territorial DD Council, we need Congress to amend the DD Act to increase the effectiveness of DD Councils to carry out this important mandate. Many of our recommendations are intended to help Congress clarify that funds provided under the Basic State Grant Program are short-term investments in long-range results; that allotments ranging from $160,000 to a little over $3 million cannot and should not provide the often life-long services needed by people with the severest disabilities.

DD Councils have always been self-critical and have constantly sought to improve our effectiveness as advocates and we are fortunate that our Councils must contain a majority of people with disabilities and their parents, since they are the conscience of the Council movement. Having the opportunity to give Congress the benefit of our best thinking every three years during the reauthorization process allows us to contribute to the strengthening of the DD Act, and therefore our own effectiveness in improving the lives of all citizens with developmental disabilities. We appreciate being able to appear before the House Subcommittee on Health and the Environment to make our recommendations to you.

Consortium for Citizens with Developmental Disabilities

Susan Ames-Zierman 347-1234
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Co-Chairs
Task Force on
Developmental Disabilities

INTRODUCTION

The Developmental Disabilities Assistance and Bill of Rights Act (Public Law 98-527) is scheduled for reauthorization during the first session of the 100th Congress. The following document represents the best thinking of members of the Consortium for Citizens with Developmental Disabilities Task Force on Developmental Disabilities, which consists of organizations concerned about services to people with developmental disabilities and contains recommendations to improve the effectiveness of the Developmental Disabilities Act.

In general, there is widespread satisfaction with the current law and the suggestions offered here are intended to fine-tune program operations and to enhance the effectiveness of the four programs authorized by the Act: the Basic State Grant Program, the Protection and Advocacy Systems, the University Affiliated Programs and Grants of National Significance/Special Projects.

Because this law is reviewed frequently, usually every three years, it is able to reflect the newest thinking in the developmental disabilities field and to continue to be on the cutting edge of improving the lives of people with developmental disabilities. The following recommendations aim not only to keep the programs current but to look to the future.

The organizations listed below endorse the recommendations presented in this document. While in a few instances there are varying views regarding how to solve particular problems, there is consensus regarding the substance of the issue areas themselves. Such views are reflected in notes following the recommendations for the convenience of the reader.

The CCDD acknowledges and appreciates the contributions made over the years by the Senate Subcommittee on the Handicapped and the House Subcommittee on Health which have improved the Developmental Disabilities Act. We look forward to working with Members of Congress during the up-coming reauthorization process. For further information, contact the co-chairs of the Developmental Disabilities Task Force indicated above.

RECOMMENDATIONS REGARDING THE REAUTHORIZATION OF
THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

PROGRAMS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

PART A - GENERAL PROVISIONS
FINDINGS AND PURPOSES (Section 101)

ISSUE #1: During the 1984 reauthorization, the purposes of the Developmental Disabilities Act were refined and expanded to include increasing the independence, productivity and integration into the community of people with developmental disabilities. In the three years' experience operating under these expanded purposes, attention has been focused more clearly on the capabilities as well as needs of persons with developmental disabilities. Also, assistance to parents was greatly enhanced in PL 98-527 and new efforts in this arena have increased awareness of the importance of providing support to families in their desire to ensure that their family member will be able to live in the community throughout life. Therefore, to strengthen further the statement of purpose in the Act, the following is recommended.

RECOMMENDATION: Include individual and family empowerment as one of the purposes of the Developmental Disabilities Act.

DEFINITIONS (Section 102)

RECOMMENDATION: Add a new definition of the term "individual and family empowerment." Section 102 (11)

ISSUE #2: Several recommended changes in the State Plan and priority areas will require modifying definitions. The first is the titles of the priority areas.

RECOMMENDATION: Modify three of the four terms used for federal priority areas as follows: community living (from alternative community living arrangements), employment (from employment related activities), and child development (from child development services). Part (11)(C) to become (12)(C)

ISSUE #3: Add the term and define "applied technology"

RECOMMENDATION: The term "applied technology" means the systematic application of technology, engineering methodologies or scientific principles to meet the needs of and address the barriers confronted by individuals with developmental disabilities in areas including education, employment, supported employment, transportation, independent living and other community living arrangements. Section 102 (11)(H)

ISSUE #4: Because Developmental Disabilities Councils, Protection and Advocacy Systems and University Affiliated Programs have emphasized employment since 1984, there has been a broader investigation of the needs of adults with developmental disabilities in general, resulting in an awareness of the critical need to develop state-wide systems of case management. After studying the state of case management in the states, changes in its definition are suggested. Further, it needs to be made clear that the role of the DD Council in this priority area is to assist in the design and development of state-wide case management systems.

RECOMMENDATION: The term case management should be redefined as follows. Part 11(h)

Case management means a potentially life-long, goal-oriented process for coordination of the range of services needed by persons with developmental disabilities and their families. Case management is designed to ensure accessibility, continuity of care, and accountability and to ensure that the maximum potential of persons with developmental disabilities for independence, productivity, and integration into the community is attained. Case management, at a minimum, includes:

(a) outreach to identify eligible individuals;
(b) assessment and periodic reassessment to determine each individual's strengths, functional limitations and needs for specific services;
(c) participation in the development of a comprehensive individualized habilitation plan (IHP) as specified in Section 123;
(d) referral to and coordination of needed social, health, educational, support and other services as identified in the individualized habilitation plan;
(e) monitoring to ensure the delivery of appropriate services to the individual and his/her family and to determine progress in meeting goals and objectives specified in the IHP;
(f) advocacy to assist the individual in obtaining all services to which s/he is entitled and to effect changes in the service delivery system that will result in the individual's increased access to services. Section 102(11)(H) becomes Section 102(11)(I)

ISSUE #5: There are many activities which do not fit into the four federal priority areas and thus, if critical to the development of a comprehensive system of community services, must be described in terms of one or the other of the four priority areas or not done. The four federal priority areas are not mutually exclusive and by no means cover all possible activities needed on the state level for persons with developmental disabilities. Changes in the language authorizing a state optional priority during the last reauthorization have precluded using the state option as a vehicle for such activities in most states. For future policy purposes and for monitoring of the program, a full reinstatement and redefinition of the state priority area is needed. The

states which have selected state priorities in the past have done so for very explicit reasons and their activities frequently indicate innovative activities which are helpful in planning future reauthorizations of the Act. Most states are now precluded from continuing those efforts. Several states have used their state option to stimulate, develop, maintain and/or train state-wide networks which can assist in implementing state plan objectives for policy change on the state and local levels. People in these networks, parents, professionals, people with disabilities and others, need to be trained and supported in policy and service issues. This capacity-building activity clearly supports the role of the DD Council as advocate described in the Act and represents the kind of activity intended by Congress to achieve the law's purposes.

People with developmental disabilities also have needs that are structural in nature, i.e., services or activities that must undergird a state's system, such as the development/coordination of rural services; consumer self-advocacy; public education/awareness activities regarding developmental disabilities; transportation services to enable people in residential programs to be able to work; socio-legal and protective services; prevention activities which go beyond early childhood-related issues; the support of technological developments for people with developmental disabilities; information and referral; outreach to unserved or underserved groups; community acceptance/ organization; and other similar activities which go beyond the definition of any single federal priority area. These activities and others like them are essential to the development of a comprehensive system of services in our nation. Such innovative and successful activities do not "show up" clearly when reporting on the program and need to be monitored and shared to give direction for future federal policy and to enable states to learn from one another.

> RECOMMENDATION: The state optional priority area should be fully reinstated and its selection should be at the discretion of the states. It should not be conditional upon a demonstration that the federal priority areas are no longer needed, but upon a demonstration of the importance of such state priority activities to the development of a comprehensive array of services. A suggestion for a new definition of the optional state priority area is: "activities which effect positive change in specialized or generic services for persons with developmental disabilities, which are deemed essential by a State in achieving desired outcomes in its State Plan and/or which address two or more federal priority areas." Section 102(12)(A)(ii)

Issue #6: The Basic State Grant Program provides modest allocations to states for activities which build the capacity of the public and private sectors to provide services to people with developmental disabilities. These funds act as catalysts for state and local public and private dollars. These capacity-building activities should be reflected in the Act, emphasizing that Developmental Disabilities funds are for seeding, demonstrating and catalyzing permanent services financed under other authorities and through other means.

RECOMMENDATION: Language permitting the "provision of specialized services" in the priority areas should be deleted and the activity permitting "model service programs" should be modified to clarify that such programs are for demonstration purposes (i.e., model demonstration programs) Section 102(1)(R)(i) and (ii)

ISSUE #7: One of the most successful methods of DD Council advocacy for services is the dissemination of the results of studies of state policies which pose barriers to the independence, productivity and community integration of people with developmental disabilities. Best results in states frequently occur when the state legislature and/or Governor has been convinced by compelling facts that harmful laws should be changed or that new legislation is needed to meet identified needs. These activities need to be emphasized in the Act as service activities.

RECOMMENDATION: Language to include "policy analysis and educating policy makers" should be added to the definition of the term "service activities." Section 102(B)(viii).

Issue #8: Support to individuals and families is a vital component of successful community living. The definition of the community living priority area does not sufficiently specify individual and family support services.

RECOMMENDATION: Insert the words "individual and" before "family support services" in the definition of the federal priority area of community living. Section 102(D)

ISSUE #9: The Developmental Disabilities Programs were enacted to assure quality services for individuals who have severe and chronic disabilities. Since many state statutes still contain the "old" definition of developmental disabilities (listing categorical disabilities) the federal law needs to emphasize that Basic State Grant activities must be directed toward objectives, programs and resources for people who meet the requirements of the definition of developmental disabilities in Section 102(7)(A) through (E).

RECOMMENDATION: Committee report language should emphasize that federal law supercedes state statute with respect to the DD definition, that state plan activities should address the needs of those who meet the federal definition of developmental disabilities and DD Councils should be periodically required to review activities of subgrantees to ensure that the requirements of the federal definition are being met.

ISSUE #10: States are at various levels of sophistication in the design and provision of services to people with developmental disabilities, even though a great deal has been learned in recent years. To assist states, Congress should express its desire for programs funded under the Basic State Grant to be evaluated against best practices.

RECOMMENDATION: Committee report language should stress that activities funded under the Basic State Grant program are to be evaluated against professionally accepted best practices.

PART B - FEDERAL ASSISTANCE FOR PLANNING AND SERVICE ACTIVITIES
FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

STATE PLANS (Section 122)

ISSUE #1: Overwhelmingly DD Councils feel that the restriction on the number of federal priority areas a state may select is arbitrary and prevents states from clearly describing many cross-cutting and interagency initiatives in a precise way. Because the federal priority areas are very broadly defined and and inter-related and because the development of a comprehensive system of services may require the selection of all areas at any given time, the states need to be able to select up to the maximum number of federal priority areas. State Plans should continue to require that Councils indicate the percentage of funds allocated to each.

RECOMMENDATION: Eliminate the restriction on the number of federal priority areas a state may select. Beginning in fiscal year 1988, the plan should be required to provide for at least one federal priority area and be permitted to provide for up to four federal priority areas. Section 122(b)4(B)(i)I. (See note 1)

Issue #2: States should be permitted to select a state optional priority area if it is deemed essential to the the development of a comprehensive array of services for people with developmental disabilities and/or if the activity addresses activities which overarch two or more of the federal priority areas. (See discussion under issue #5 on page 2 in the previous section.)

RECOMMENDATION: Notwithstanding the requirements of subparagraph (B) at the option of the State, the State may provide for one or more additional activities addressing services for persons with developmental disabilities (as defined in Part A Section 102 (11) (A)(ii) which are deemed essential to the development of a comprehensive array of services and/or provision of two or more the federal priority area(s). The State plan must describe and provide an assurance regarding the need for such State optional priority or priorities. Section 122(b)(4)(B)(I)(iii).

Issue #3: Current law requires all states to select the priority area of employment in FY 1987 and thereafter. Even before this requirement, 43 Councils were actively pursuing employment, indicating that the new priority area rightly identified a need. Since all states have now embarked upon the employment priority area it is no longer necessary to require such selection. The mandatory selection of employment has served its purpose of getting states involved in the area. In addition, since capacity-building activities in all priority areas tend to be long-range, states can be expected to continue working in this area without a federal mandate to do so.

RECOMMENDATION: Eliminate the requirement to select employment related activities as a federal priority area. Section 122(b)(4)(B)(ii). (See note 2)

Issue #4: In the 1984 reauthorization of the DD Act, a provision was added requiring that the state provide the DD Council a copy of any plans of correction for intermediate care facilities for persons with mental retardation and developmental disabilities (ICF/MR/DD) received by the state. No specific action was required, however, beyond receipt of the document(s).

> RECOMMENDATION: The DD Councils' Annual Report should describe actions taken by the State pursuant to any annual survey reports or plans of corrections for cited deficiencies prepared pursuant to section 1902(a)(31)(B) of the Social Security Act with respect to any intermediate care facilitaties for the mentally retarded/ developmentally disabled in such State and should describe the response of the DD Council to such reports, plans and actions. (See note 3)

ISSUE #5: For more than a decade the most serious, recurring problem facing the DD Basic State Grant Program has been untoward control of State Planning Council actions, funding decisions and advocacy strategies by the designated state administering agency for the program. Previous attempts to correct such situations have been ineffectual.

In addition, the concept of administering agency/agencies as currently in the Act is antiquated, given the change in the role of Councils in recent years. There are no Councils which have more than one administering agency at this time. At present, because DD Councils (with the exception of California) are not designated "state agencies" in state statute, they are technically unable to administer Basic State Grant funds. Each state must have an entity authorized by state government to receive, disburse and account for federal funds. Attempts by administering agencies to control DD funds for purposes other than those intended by the Council have created many difficulties in many states. The Administration on Developmental Disabilities provided program guidelines regarding the organizational location of DD Councils in 1977, which has never been clarified in statute, thus permitting considerable interpretive latitude. The issuance states that "the Council should be organizationally located with appropriate stature and resources within the state system to effectively advocate for developmentally disabled persons (sic)...by having the Council located within (1) the immediate Office of the Governor, (2) the State Planning office, or (3) the immediate office of the head of the administering agency. In any case, however, the Council shall report directly to the Governor." DD Councils and the CCDD have discussed various methods for overcoming these serious problems and have concluded that since there is no single solution which will help all states, an incremental step can be taken to begin to address the issue.

> RECOMMENDATION: Clarify that there is a single state agency needed to administer the program and permit DD Councils to be their own administering agency, similar to the Early Intervention Councils authorized under the Education for Handicapped Children Amendments of 1986. Second, clarify that expenditures in support of the priority areas must be guided by the decisions of the DD Council. And third, reflect the 1977 policy issuance outlined above. (See note 4)

ISSUE #6: Demographic studies have shown that there is a need to address America's aging population. Services to elderly people who have developmental disabilities need to be planned and coordinated with services authorized by the Older Americans Act.

RECOMMENDATION: Add the aging plan (developed pursuant to the Older Americans Act) to the list of other state plans for federally assisted state programs to be described in the DD state plan. Section 122(2)(C)(i)

ISSUE #7: To address the state optional priority, the state should be required to assure that it is needed and should be required to provide a rationale in the State Plan.

RECOMMENDATION: Add the following assurance to Section 122(b)(3): (G) in the event a State selects priority activities in addition to the federal priority areas, that such additional activities are essential to successful implementation of the State Plan.

ISSUE #8: Staff for the state Planning Council are usually employees of the state's civil service system. They provide support to the Council and, at the same time, are employed by a state agency that administers the program. This places Council staff in a position of "serving two masters" and conflicts occur between agency policy and Council advocacy efforts. For example, if the DD Council takes a policy position with which the agency disagrees, the Council staff director may be precluded from implementing that decision. This weakens the effectiveness of the DD Council in its role as advocate. In addition, Council staff have frequently been assigned responsibilities by the administering agency which are not directly related to the support of the Council and its decisions, in violation of Congressional intent and administration policy issuances. Because funds for the Basic State Grant program are limited, this further reduces the staff's capacity to carry out the mandates of the program. Congress has made clear in Conference Report No. 94-473 that the Council staff should have responsibilities only to the Council and not to the administering agency. The report further clarifies that instructions to and supervision of Council staff must take place directly between the Council and its staff. To ensure that Congressional intent is implemented, the law must contain a clear prohibition of such inappropriate interference with the activities of Council staff.

RECOMMENDATION: Add statutory language which reflects the 1978 Conference Report and ADD policy issuances regarding personnel to the Developmental Disabilities Council, requiring that they be in such numbers and have such qualifications to enable the Council to carry out its duties under this title, that Council staff not be assigned duties by the administering agency, and that instructions to and supervision of Council staff must take place between the Council and its staff. Section 122(b)(3)(H). (See note 5)

ISSUE #9: While many people with developmental disabilities have mental retardation, there are other individuals with severe disabilities who have no cognitive impairment. Although all people with developmental disabilities have many needs in common, the latter group have special concerns which need to be addressed.

RECOMMENDATION: The state plan should indicate what resources are available in the state for people with developmental disabilities who do not have mental retardation and ways in which the Basic State Grant program intends to address identified gaps in services. (See note 6)

STATE ALLOTMENTS (Section 125)

Issue #10: Minimum allotment states and territories have struggled with limited funds to provide core functions required of all DD Councils, regardless of the size of the state/territory. There is a need to increase the minimum allotment.

RECOMMENDATION: In any case in which amounts appropriated under Section 130 for a fiscal year exceed $60,000,000, the allotment under paragraph (1) for such fiscal year

(A) to each of American Samoa, Guam, the Virgin Islands and Commonwealth of the Northern Mariana Islands or the Trust Territory of the Pacific Islands may not be less than $200,000; and

(B) to each of the several States, Puerto Rico, or the District of Columbia, may not be less than $350,000.

(C) For any fiscal year in which an increase in appropriation for that year is greater than the Consumer Price Index percentage increase, the Secretary shall be permitted to increase the minimum allotment administratively. Section 125(a)(4)

AUTHORIZATION OF APPROPRIATIONS (Section 130)

ISSUE #11: The following appropriations levels are recommended.

RECOMMENDATION: For allotments under section 125, there should be authorized to be appropriated $62,200,000 for fiscal year 1988, $69,900,000 for fiscal year 1989 and $77,400,000 for fiscal year 1990.

PART C - PROTECTION AND ADVOCACY OF INDIVIDUAL RIGHTS

PURPOSE (Section 141)

ISSUE #1: The purpose of the Protection and Advocacy System should closely reflect the overall purpose statement in the Act.

RECOMMENDATION: Add after "of persons with developmental disabilities" the phrase "to assure that they receive the services necessary to enable them to achieve their maximum potential through increased independence, productivity and integration into the community."

SYSTEM REQUIRED (Section 142)

ISSUE #2: Minority persons who have developmental disabilities have been a priority for service for many Protection and Advocacy agencies. The Department of Health and Human Services has provided funds in the past for P&As to develop outreach programs for minority persons with developmental disabilities through demonstration grants from the Office of Civil Rights and the Administration on Developmental Disabilities.

RECOMMENDATION: A specific focus to meet the needs of underserved minority persons needs to be added to the Act.

ISSUE #3: Protection and Advocacy agencies, because of insufficient resources, have not adequately addressed the needs of persons with developmental disabilities who become involved in the criminal justice system.

RECOMMENDATION: A specific focus to address the needs of persons with developmental disabilities involved in the criminal justice system should be added to the Act.

ISSUE #4: The P&A programs have been heavily involved in the enforcement of P.L. 94-142, the Education for All Handicapped Children Act. P&As report 40% of their cases involved special education issues. This effort must be further enhanced.

RECOMMENDATION: Reports from the Office of Special Education at the U.S. Department of Education and the state monitoring reports of local education agencies must be provided to the P&A systems.

ISSUE #5: The P&As must be able to advocate for persons with developmental disabilities before all appropriate governmental entities such as boards, commissioners, city and county councils and state legislatures.

RECOMMENDATION: Language should be included in the P&A authority to make clear that the P&A systems may advocate before appropriate public bodies on behalf of people they serve.

ISSUE #6: Several P&As use subcontracts to achieve a full range of advocacy services throughout the state. From time to time, subcontractors will return unexpended funds in the next fiscal year which the P&A cannot use for recontracting of services. Use of these funds should be allowed with timelines on reobligation and liquidation.

RECOMMENDATION: A carryover of 10% of the yearly allotment should be allowed to give flexibility in management of funds and to avoid problems of obligation of money.

RECOMMENDATION: Funds which were obligated in the current fiscal year but are subsequently returned in the next fiscal year should be available for reobligation and should not be required to be returned to the federal government.

ISSUE #7: Protection and Advocacy Systems engage in a priority setting process at least every three years and many review priorities annually. Community input would enhance the process and assure accountability of the system.

RECOMMENDATION: Provide for input by the disability community in the planning and priority setting activities of the Protection and Advocacy Systems.

ISSUE #8: Protection and Advocacy Systems, like any service provider, should be accountable to individuals whom they serve. At times clients are dissatisfied with the handling of their cases and should be afforded the opportunity to challenge the decision of the Protection and Advocacy System regarding their case. Recognition should be made, however, of the extensive P&A mandate and the limited resources available to carry out this mandate and the impact this limitation poses regarding responding to such complaints.

RECOMMENDATION: Provide for a client grievance procedure within the P&A agency to assure that persons with developmental disabilities have full access to advocacy services.

ISSUE #9: Based on the continued depopulation of state institutions and nursing homes as well as the relocation of individuals within community living arrangements, a large number of individuals are being moved with no advocacy or legal representation.

RECOMMENDATION: Language should be included to provide the Protection and Advocacy Systems standing and representation in all situations where an individual over the age of 18, who has no family or legal guardian other than the state or county (who have potential conflicts of interest), is being considered for a change in his/her living arrangement to assure that the proposed new arrangement is appropriate to the individual's needs and that the services needed are in place or will be in place prior to such a move.

AUTHORIZATION OF APPROPRIATIONS (Section 143)

ISSUE #10: The minimum allotments should be readjusted to enable P&As in all states to provide an adequate level of service.

RECOMMENDATION: The Commissioner of the Administration on Developmental Disabilities should have the option to raise minimums administratively in years in which an appropriation increase for that year is greater than the Consumer Price Index percentage increase.

RECOMMENDATION: The minimum allotment should be raised automatically to $250,000 when the appropriation reaches $20 million.

ISSUE #11: Based upon increased mandates for expanded services described above, the authorization levels for P&As need to be increased.

RECOMMENDATION: Authorization of appropriations for FY 1988 should be $25 million; for FY 1989, $28 million and for FY 1990, $31 million.

PART C- UNIVERSITY AFFILIATED PROGRAMS

ISSUE #1: The UAP network has not had the necessary federal funding resources to meet the training expectations of the developmental disabilities field. As such, UAPs have diversified in many areas, seeking funds from a variety of federal, private and state agencies in an effort to obtain the critical mass to address the training role. Present information suggests that this trend is growing steadily worse. The core funds provided by the Developmental Disabilities Act to the UAP network need to be increased.

RECOMMENDATION: Authorization levels for the minimum allocation or core funding of full UAPs should be increased to $300,000 and satellite UAPs to $220,000.

ISSUE #2: There are currently 15 states (Hawaii, Alaska, Nevada, Idaho, Wyoming, North Dakota, Oklahoma, New Mexico, Arkansas, Illinois, Delaware, New Hampshire, Maine, Texas and Rhode Island) that do not have a DD-UAP. Consequently, these states suffer in at least two ways. First, there is no in-state mechanism to provide the specialized personnel preparation for the various programs that serve children and adults with developmental disabilities. Second, few - if any - programs in a state without a UAP can meet the interdisciplinary needs of "dually diagnosed" children (i.e., those youngsters with both mental retardation and some other disabling condition). In the vast majority of cases, community providers, hospitals, the State Title V Programs for Children with Special Needs (formally State Crippled Children's Services Programs) and other programs simply do not have the staff, resources and equipment necessary to provide effective services to these children.

RECOMMENDATION: At minimum, each state should have one UAP. Congress should make available $30,000 for each of the 15 in FY 1988 for the conduct of simultaneous feasibility studies (currently required by ADD) to enable these states to have satellites or full UAP by FY 1989. There are currently seven satellite UAPs, many of which are ready to become comprehensive UAPs. Funds obligated for new satellites should be added to existing UAP appropriations and phased in over a two-year period. Therefore, no new programs should be created until the requirements of the appropriations trigger outlined above are met. (See Issue #6 below) Funds needed in FY 1988 total $450,000.

ISSUE #3: The demand for allied health professionals trained in the developmental disabilities field has increased, placing a substantial burden on an inadequate pool of skilled personnel. Specifically, many more trained specialists in a wide variety of fields are needed to develop the individual education and service plans (IEPs/ISPs) mandated by existing law and required for effective service delivery. There is a great need for personnel with interdisciplinary training, particularly for staff to provide services authorized by the new early intervention program in the Education of All Handicapped Children Amendments of 1986 (P.L.99-457). This program would assist states to develop and implement statewide, comprehensive, coordinated, multidisciplinary, interagency programs of early intervention services for handicapped infants and toddlers and their families (specifically infants from birth to three).

RECOMMENDATION: The authorization of $1 million to provide support for five to seven pilot development and implementation training projects (each approximately $150,000 to $200,000) through 1990. The tasks of each pilot training project will be to plan, design and implement an interdisciplinary training program to help prepare allied health professionals needed to provide early intervention services.

A standard application process administered by the Secretary should be used. A UAP prior to submitting its application, must inventory local community-level direct care and paraprofessional training programs to seek their guidance and input in the preparation of applications. Such applications would demonstrate that any UAP-provided training would be explicitly coordinated with these local programs.

ISSUE #4: There is increasing integration into the community of persons with developmental disabilities and, therefore, an expanding need for direct care personnel for community-based service programs. There has been a dramatic increase in the need for personnel with interdisciplinary training because of the overall expansion in badly needed community-based day and residential services to persons with developmental disabilities. Existing training programs are ill-funded and essentially ad hoc in nature. There is a need to focus a new training program to prepare hands-on, direct care personnel and paraprofessionals who are employed in community-based residential programs.

RECOMMENDATION: Authorize the demonstration and implementation of five to ten training programs for direct care workers and paraprofessionals at a level of $1 million for FY 1988, $1 million for FY 1989 and $1 million for FY 1990.

A standard application process administered by the Secretary should be used. A UAP, prior to submitting its application, must inventory local community-level direct care and paraprofessional training programs to seek their guidance and input into the preparation of the application. Any UAP provided training will be explicitly coordinated with these local programs. (See note 7)

ISSUE #5: Available data suggest that the number of elderly people with developmental disabilities is substantial and growing rapidly. Current national estimates indicate that there are over 200,000 individuals with severe disabilities who are 55 or older. Just 15 years from now that figure could realistically double. Our existing service and training systems are unprepared to address the needs of this burgeoning group. A major reason for the lack of appropriate services (or, in many cases no services at all) is the lack of trained personnel at all levels, from geriatricians to nutritionists.

RECOMMENDATION: Authorize 10 UAPs to provide cross-training in the developmental disabilities field and in the aging field for geriatricians, internists, nurses, social workers and other allied health professionals. Authorize appropriations of $1.167 million per year.

ISSUE #6: According to funding data published by Dr. David Braddock of the University of Illinois in a recent study entitled, "Federal Spending for Mental Retardation and Developmental Disabilities," the Administration is spending - in real terms - one million fewer dollars on UAPs today than it did at the inception of the program in 1972 ($4.25 million in FY 1972 compared with $3.345 million in adjusted dollars as of FY 1985). Moreover, the individual programmatic responsibilities and the number of persons served by UAPs (now over 75,000 children and adults nationwide) have also increased substantially over the last 15 years.

RECOMMENDATION: For the UAP authority, authorization of appropriations should be $15.927 million in FY 1988; $19.387 million in FY 1989; and $20.267 million in FY 1990. The trigger for new programs to be funded is recommended at $19.387 million in FY 1989. In view of the expansion proposals discussed above, an appropriations trigger is needed to maintain existing programs. These recommended authorization levels encompass all UAP programmatic recommendations and initiatives contained in this section.

PART E - SPECIAL PROJECT GRANTS

ISSUE #1: For many years, advocacy organizations have been dissatisfied and disappointed with the overall results of Special Projects funded under this authority. The needs of the developmental disabilities community for nationally significant activities are greater now than ever and, as funds for Special Projects were reduced over time, less and less has been available for the kinds of activities which provide information enabling states and federal policy makers to base decisions on facts. This authority needs to be totally restructured and carefully monitored by Congress.

RECOMMENDATION: Re-title Part E to Nationwide Policy Initiatives to Improve Services to People with Developmental Disabilities.

PURPOSE (SECTION 161)

RECOMMENDATION: The purpose of Part E should be "to provide funds for grants and contracts for up to five years to public and/or non-profit private agencies for initiatives which have an impact on national policy to improve services to people with developmental disabilities through: (1) data collection and dissemination; (2) technical assistance; and (3) federal interagency initiatives.

GRANT/CONTRACT AUTHORITY (SECTION 162)

ISSUE #2: A major problem with the current program is that it does not fund on-going data collection activities needed to provide the nation and Congress with the information vital to policy decisions affecting people with developmental disabilities. In addition, many demonstration projects funded by Part E are inappropriate for federal funding and should, in fact, be demonstrated at the state and local levels. Such demonstrations should no longer be funded by this authority. Some of the most outstanding special projects in the past have been various policy analyses which provide needed data to enable states and the federal government to document problems and opportunities presented by state and federal policy.

In addition, the programs authorized by the Developmental Disabilites Act, the Basic State Grant Program (Councils and their Administering Agencies), Protection and Advocacy Agencies, and University Affiliated Programs have information regarding services to people with developmental disabilities that has not been collected and shared nationally. A database should be required which will be on-going, up-dated and widely available to groups, agencies and individuals. Such a database would significantly improve (1) overall program accountability (Congress and the administrative agencies could monitor the progress of all four program components to determine how well they are meeting their statutory objectives); (2) communication and sharing of information among state agencies, UAPs, DD Councils and P&As, reducing duplication of effort and receiving maximum benefit from limited resources; and (3) the ability of policy-makers to track current trends and adjust the service delivery systems. If sufficient funds are provided, the data base could collect and disseminate data from a broad range of additional programs and projects, including projects funded under this authority, forming the basis for programmatic initiatives across federal agencies. Such data collection, analysis, dissemination and data base development should be one of the major functions of this discretionary authority.

RECOMMENDATION: $1 million should be earmarked for the on-going collection of data to be used for policy analysis and dissemination on a nationwide scale regarding policies and services affecting persons with developmental disabilities, including but not limited to activities which (a) collect and disseminate data regarding federal and state funding of services for persons with developmental disabilities under various federal and state authorities and (b) collect and disseminate data regarding the activities and effectiveness of the DD Councils, Mental Retardation/Developmental Disabilities State Agencies, the Protection and Advocacy Systems, the University Affiliated Programs and the National Policy Initiatives authority.

ISSUE #3: The availability of on-going technical assistance to improve the effectiveness of the programs authorized by the DD Act is woefully lacking and desperately needed. As the regional HDS offices have consolidated from ten to four, and as staff of the Office of Human Development Services has been reduced, programmatic and management assistance has declined to almost nothing. An on-going technical assistance capability needs to be assured to share state information nationally and to provide specific assistance to improve the three programs at the state level. Technical assistance should be the second major function of this discretionary authority.

RECOMMENDATION: $400,000 should be earmarked for the on-going development and provision of training and technical assistance to Developmental Disabilities Planning Councils, Protection and Advocacy Systems, University Affiliated Programs and Developmental Disabilities State Agencies. (See note 8)

ISSUE #4: Finally, federal funds under this authority should reflect the capacity-building nature of the state programs and should be used as a catalyst for agencies outside of ADD to serve people with developmental disabilities under other authorities. Also, through such interagency activities, ADD will gain expertise in the wide range of federal/state programs which have an impact on people with developmental disabilities. Potential federal agencies with which cooperative projects could be rfunded include: the Social Security Administration, the Department of Housing and Urban Development, the Department of Labor, the Office of Special Education and Rehabilitative Services, the Health Care Financing Agency, and other divisions within the Office of Human Development Services, etc. Federal interagency initiatives should be the third major function of this discretionary authority.

RECOMMENDATION: $1 million should be earmarked for federal interagency initiatives which are nationally significant in increasing the capacity of states to serve people with developmental disabilities.

ISSUE #5: There is a need to provide information to (1) parents and people with disabilities regarding services that are available in their part of the country; (2) professionals regarding both service availability and consulting expertise in various organizations and/or in particular specialized areas; (3) professionals and consumers alike regarding model programs, publications and resource materials and ongoing research projects. A major thrust of a system design would be to coordinate and link already existing computerized information and referral systems in states and communities.

It is proposed that one to three studies be conducted to test the feasibility of the development of a nationwide information and referral system. The study or studies would examine currently operating local, state, regional and national systems in the various programmatic fields listed above to determine whether or how they could be coordinated and integrated into a national network. Should the study conclude that a coordinated I&R system of national scope would be possible, cost effective, meet state and local needs and increase access to services, the design phase would take place in the second year. In the third year, technical assistance would be provided to states and localities in the design, operation and national linkage of their own I&R systems.

> RECOMMENDATION: $250,000 should be earmarked in FY 1988 for the initial feasibility study, $250,000 in FY 1989 for the design phase and $250,000 in FY 1990 for technical assistance.

ISSUE #6: Since 1983, funds authorized under this Part have been co-mingled with funds authorized by other programs of the Office of Human Development Services which provide services to Native Americans, foster and adopted children, and the aging. Requests for proposals have focused on "cross-cutting" projects which address the common needs of combinations of these populations. Since the DD Special Projects Program is small, this dilution of the focus on issues addressing the specific needs of people with developmental disabilities should be prohibited. Opportunities for creative interagency initiatives have been proposed in Issue #4 above.

> RECOMMENDATION: Prohibit the inclusion of DD Special Projects funds in the Office of Human Development Coordinated Discretionary Fund.

ISSUE #7: The identification of issue areas in which to fund activities under this section needs to be opened to a public process whereby experts in the field, parents, and people with disabilities have an opportunity to provide input to the Administration on Developmental Disabilities regarding the most critical needs. While ADD should retain some discretion in the areas to be funded and exert stewardship of this program, particularly in the area of interagency initiatives, all too often the funding areas selected have been tangential, at best, to the greatest needs in the developmental disabilities field.

RECOMMENDATION: ADD should be required to solicit views from the field prior to the publication of the announcement of the priority areas selected for funding under this authority and should be further required to respond to the suggestions, indicating which were heeded, which were not, and why.

ISSUE #8: Authorization of appropriations levels should reflect activities described above.

RECOMMENDATION: Authorization levels for FY 1988, $2.65 million; for FY 1989, $2.78 million; and for 1990, $2.92 million.

SUMMARY TABLE OF RECOMMENDED AUTHORIZATION OF APPROPRIATIONS
DD ACT PROGRAMS
(in millions)

	FY 1988	FY 1989	FY 1990
BASIC STATE GRANT PROGRAM	62.2	69.9	77.4
PROTECTION AND ADVOCACY SYSTEMS	25.	28.	31.
UNIVERSITY AFFILIATED PROGRAMS	15.927	19.387	20.267
NATIONAL POLICY INITIATIVES	2.65	2.78	2.92
TOTAL	105.777	120.067	131.587

NOTES

(1) Part B, Issue #1. United Cerebral Palsy Associations, Inc. (UCPA) believes that Councils should not be permitted to expand the number of federal priority areas they may select. The current state plan priority setting mechanism provides a forced choice decision-making process to have the state focus its resources on only three priorities to assure maximum impact and effectiveness of limited resources. Increasing the allowable federal priorities to four may lead to a more political decision making process and to a reduction of the impact and effectiveness of the program. UCPA agrees with the next recommendation, however, permitting states to select a state priority in addition to three federal priority areas.

(2) Part B, Issue #3. UCPA and the Epilepsy Foundation of America (EFA) believe that the mandated selection of the federal employment priority area should be retained as one of the state's three federal priorities. The largest single "bottleneck" in almost every state system for persons with developmental disabilities is the so-called "aging out" problem for children leaving their entitlement to a free appropriate public education under P.L. 94-142, the Education for All Handicapped Children's Act of 1975, and waiting for adult services. Employment services must be continued to assure implementation of new adult strategies and options promoting greater integrated employment opportunities for adults with developmental disabilities.

(3) Part B, Issue #4. The Association for Persons with Severe Handicaps (TASH) agrees with the recommendation as stated and would like to add a requirement that the state DD Council should review and comment on all changes affecting people with developmental disabilities in the state Medicaid plan to prepare for anticipated reforms in the Medicaid program. While current law already requires Councils to annually review Medicaid plans, there are problems in implementation which should be corrected in report language.

(4) Part B, Issue #5. UCPA amd TASH agree that Councils should be permitted to be their own administering agencies but believe there is a major problem with the recommendation if it does not goes beyond that. More than half of the DD Councils are administered by agencies which provide or fund services to people with developmental disabilities and/or other categories of persons with disabilities, placing DD Councils in obvious conflict-of-interest situations. DD Councils must be able to make decisions in an environment free of conflict of interest and without any potential for reprisal by the administering agency which may well have different needs, statutory requirements and priorities. In further support of the above recommendation, UCPA also notes that at least 20 state agencies currently administering the DD Program have no statutory authority or responsibility to meet the needs of people with developmental disabilities other than mental retardation. (See ARC comments regarding note 6)

(5) Part B, Issue #8. The National Association of State Mental Retardation Program Directors (NASMRPD) and the National Association of State Mental Health Program Directors (NASMHPD) agree that Council staff should be accountable programmatically to the Council. However, if Congress chooses to include this existing regulatory requirement in the statute, it should be made clear that Council staff personnel are administratively accountable to the appointing authority. This modification can be accomplished by adding the phrase, "and are administratively responsible to the designated state administering agency."

(6) Part B, Issue #9. The Association for Retarded Citizens - U.S. (ARC), the American Association on Mental Deficiency (AAMD), the National Association of State Mental Retardation Program Directors (NASMRPD), and the National Association of State Mental Health Program Directors (NASMHPD) have serious concerns about the recommendation to require State Councils to begin to distinguish between mentally retarded and non-mentally retarded people with developmental disabilities for purposes of planning and funding programs. It is important to remember that the original purpose of the Act was to focus on functional needs of persons with severe disabilities originating in childhood who are generally denied access to other generic and specialized systems. Most individuals with developmental disabilities have mental retardation. The vast majority, if not mentally retarded, have similar needs. To separate these two groups is impractical, flies in the face of the very basis of the Act and will ultimately divide the DD constituencies at all levels. The above organizations believe that the law not should not be amended as recommended.

On the other hand, UCPA believes the recommendation does not go far enough and believes it can demonstrate a clear record of Basic State Grant funds being targeted almost exclusively to persons with mental retardation. This organization feels that people with cerebral palsy, epilepsy, autism, spina bifida, and others with substantial functional limitations without mental retardation are entitled to a fair portion of the efforts of this program. Therefore, UCPA recommends that one-third of the Basic State Grant funds be earmarked specifically for system issues and services to meet the specialized needs of individuals with developmental disabilities other than mental retardation.

Regarding earmarking, the vast majority of CCDD organizations strongly oppose specifying a percentage of these funds for any particular subgroup of people with developmental disabilities. A large portion of citizens with developmental disabilities have multiple handicaps. To attempt to single out some for services while excluding others based on the category of their disabilities is blatantly discriminatory and violates the very basis on which the DD Act was created, especially in view of the fact that the fundamental aim of the Act is to stimulate cross-cutting endeavors rather than to provide basic operating support for service programs. State Councils and the state planning process should remain the mechanisms for deciding service priorities and allocations. The federal government should not set arbitrary spending patterns for State Councils nor should it put one segment of the developmentally disabled community against any other. This would simply replicate many of the administering agency control problems currently experienced at the state level and would likely destroy or jeopardize the planning process and the highly beneficial cooperative arrangements between and among DD groups in the states.

(7) Part C, Issue #4. NASMRPD and NASMHPD wholeheartedly agree that more attention needs to be given to training para-professionals to work in community day and residential programs for persons with developmental disabilities. These organizations also agree that University Affiliated Programs can play a constructive role in this process. However, given the limited amount of funds that would be directed to this area, NASMRPD and NASMHPD believe that: (a) funds should be earmarked for those purposes under the Special Project authority (Part E) rather than the UAP authority, to permit states a wider range of choices in organizing a system for training community workers, and (b) the purposes for which such funds are made available should be limited to the assessment of existing training resources and unmet needs, the preparation of statewide plans for addressing current and future manpower needs in this area and the demonstration of new, improved methods of using and coordinating training resources statewide.

(8) Part E, Issue #3. NASMRPD AND NASMHPD agree that technical assistance is needed, but feel that the statutory aims of such assistance should be broadly conceived, rather than narrowly focused on the needs of DD Councils, UAPs and P&As. The field of developmental disabilities is in the midst of a period of dynamic change in which views of best methods of organizing and delivering services are being reconceptualized. Technical assistance is needed to help state and local policymakers and providers of services to integrate these new concepts into their day-to-day activities on behalf of persons with developmental disabilities. DD Councils, UAPs and P&As can play a critical facilitating role in this process, provided such technical assistance is not limited to the effectiveness of these programs or the types of advice and assistance that previously have been the purview of federal regional officials.

Mr. WAXMAN. Thank you very much.
Ms. Peach.

STATEMENT OF GAYLA O. PEACH

Ms. PEACH. Good morning. I am Gayla Peach, director of the Kentucky Protection Advocacy Division.

Mr. Waxman, it is an honor to be here today to represent the 55-State and territorial protection and advocacy agencies on the occasion of the 10th anniversary of the enactment of the P&A implementing legislation. I have had the opportunity to serve persons with DD's through the Kentucky P&A system for the past decade.

I can without hesitation report to you that P&A has made a major impact on the quality of life of persons with DD's. There is no greater reward than that which comes from working along side of people with DD when they are successful in obtaining their hard fought right to be able to move towards their individual levels of independence.

There is no greater pain for P&A advocates than the knowledge that for many persons with DD there is no mandated right to the services they so desperately need.

I can in all honesty say that our work, yours and ours, has just begun. Congress, in its wisdom, gave States the opportunity to develop its P&A system in a manner that would best serve persons with DD's in their jurisdiction. In Kentucky, our P&A is and has always been an independent agency of the State government. Last year we represented 792 Kentuckians with 1,317 identified complains when they entered the system as a P&A client.

A case closure, the agency average is three complaints per client. Thirty-eight percent of our clients have more than one disabling condition. Because of the complexity of the technical issues related to client complaints our staffing pattern includes professionals from various disciplines relating to developmental disabilities in addition to our legal staff.

It is the philosophy of our agency to resolve client's complaints at the lowest level possible utilizing the court as the last avenue of resolution.

We litigate less than 2 percent of our client's complaints. However, we have a deep sense of failure when an unresponsive and often neglectful civil service system forces us to pursue the lengthy remedy of the court.

Despite the fact that our staff averaged a 6-day work week last year, we have waiting lists for advocacy services. Our priority systems that strives to employ, a value judgment on who would be for P&A intervention. We believe that advocates do not arbitrarily make these discussions. Because we place a high value on individuals with developmental disabilities we bear great burden with the mere knowledge that we cannot meet the demands for advocacy services.

We are put in an ethical catch-22 position when we know we have not adequately proceeded with outreach. How do we outreach when we are not serving the people there asking for our services?

Currently our largest waiting list in Kentucky is in the area of right to education. At the present time, we are only accepting new

cases when the child is out of school subject to suspension or expulsion, have due process hearings pending or the child is in imminent danger of physical harm in his current place.

We have employed more people in the area of education in 1987 than we have in previous years. I am amazed that we are still having to fight the same battles though more complex as we were in 1977.

We represent our clients in institutional as well as community related issues. We advocate for the expansion of quality community residential services and in-home support systems. We believe that individuals with DD's who may reside in the institutional alternative should have had the opportunity to remain in the community as long as and as independently as they desire rather than being forced into choosing the only alternative.

We believe that the Kentucky P&A should be a model for other agencies in Kentucky and internal due process procedures. The agency maintains and adheres to comprehensive policies and procedures that fosters consistent and fairly delivered advocacy services.

P&A staff have committees, task forces, and boards, dealing with the issues surrounding early education, new technology and long-term care. The staff is also involved in drafting legislation for special education funding and legislation which passed but was not funded that establishes a right to services for persons with severe developmental disabilities.

Some examples of the types of cases handled by protection and advocacy in Kentucky are as follows: a local school district placed our client in its home-bound program for 2 weeks on the grounds the student was a danger to herself or others. The school then required the mother to transport the student to the school to receive the instruction because the home-bound teacher refused to go to the student's home. That problem sounds rather familiar.

Ms. CUBARNEY. Yes, very familiar.

Ms. PEACH. The mother was not able to afford the transportation costs in addition to being unaware of her child's right to an appropriate education. Our office has been successful in securing the appropriate school based education program for this child.

A teenager with Tourett's syndrome was denied access to the State's Medicaid waiver program. The program had been designed for persons with mental retardation and related conditions. Although the young man's IQ scores were marginally high an appropriate community program requiring the kinds of supports which would appropriately serve this individual were available within the Medicaid program.

After an administrative appeals, P&A was successful in securing the appropriate program for this man. A 30-year old Kentuckian was placed in intermediate care facility because he needed an attendant to guide his wheelchair, perform all motor tasks and interpret his communication which was limited to one or two controlled gestures. He was called too severely disabled for adult activity centers as medically at risk. Repeated encouragement, negotiation and representation by P&A assisted this young man to secure an integrated community residential placement and a volunteer job.

Currently this individual is employed as a computer operator for a State university and has a part-time position making minimum wage.

Because she was Medicaid eligible another Kentuckian was placed in a nursing home despite her age and without regard to her individual needs as a person with mental retardation. Through referral and negotiation P&A assisted her in getting out of the nursing home and into an age appropriate community setting. She no longer suffers the frequent bruises and abrasions which were caused by having twice the normal clinical level of an anti-convulsive medication in her system.

Twenty-two school age children, most of whom were wards of the State were identified in a nursing home. No one in the group had ever received an appropriate education placement, and in our estimation neither had they received active treatment.

These individuals were placed either in cribs or in a bean bag chair 24 hours a day. The day program consisted of a television set being turned on, none of the individuals had ever been fitted for orthopedic braces, wheelchairs or any other identifiable assistive devices. I think we would be appalled at the number of persons hidden away in our nursing homes such as these that I have described today.

We have and continue to receive reports of individuals who are isolated in attics, basements, a shack out back and other inhumane modes of hiding family members away from society. As the criminal justice system becomes more sophisticated in recognizing persons with disabilities we are receiving more and more referrals of individuals in present and post conviction levels, most of these individuals have never been in school, many of them are unable to communicate orally and many of them have little or no understanding about the crime they have been accused of or convicted of.

In the past few months a despondent jailer called us to say he had a young woman in his jail who was beating her head against the cell and was bleeding profusely. He had made numerous attempts to seek assistance and received none.

P&A called the appropriate regional service delivery system. They interviewed the client and discussed her situation with another service agency that had some responsibility to this young woman. Their strategy was to buy the young woman a bus ticket out of town, which they did. They placed her on the bus, she road to the other side of town, got off and was back in jail before the evening sun had set. With great difficulty we were successful in securing the services this young woman desired and needed in the community. Those are a few of the many types of cases we work with each year.

If we accomplish one thing it should be that we were responding to the needs and priorities of individuals that you have so graciously allowed us to represent. The protection and advocacy system has demonstrated its effectiveness in the first decade of operation. It is anxious to reach its full potential in the second decade. However, this potential will be achieved only with adequate resources with much to address the needs of our clients.

We strongly question that such funds as necessary will not be realized through block, generic funding. We are opposed to that type of funding for programs under the Developmental Disability Act.

Thank you.

[The prepared statement of Ms. Peach follows:]

STATEMENT OF GAYLA O. PEACH

Mr. Chairman, it is an honor to be here today to represent the 55 State and territorial Protection and Advocacy Agencies on the occasion of the 10th anniversay of the enactment of P&A implementing legislation. I have had the opportunity to serve persons with developmental disabilities through Kentucky's P&A system for the past decade. I can, without hesitation, report to you that P&A has made a major impact on the quality of life of persons with developmental disabilities. There is no greater reward than that which comes from working along side of people with developmental disabilities when they are successful in obtaining their hard fought right to be able to move toward their individual level of independence. There is no greater pain for a P&A advocate than the knowledge that, for many persons with developmental disabilities, there is no mandated right to the services that they so desperately need. I can in all honesty say that our work, yours and ours, has just begun.

Congress, in its wisdom, gave States the opportunity to develop its P&A system in a manner that would best serve persons with developmental disabilities within their jurisdictions. In Kentucky, our P&A is, and has always been, an independent agency of State government. We are attached to the Public Protection and Regulation Cabinet, Department of Public Advocacy for administrative purposes only. Our P&A mandate and independence is incorporated in State statute. We receive general funds in addition to Federal funds allotted under the Developmental Disabilities Act.

Kentucky P&A has an Advisory Board. Its 17 members are primary consumers, parents, or guardians of persons with developmental disabilities, and representative from State-wide DD related advocacy groups as well as the Director of the Human Develop Institute.

Although Kentucky P&A provides information and referral services as well as training, its major emphasis is direct representation of persons with developmental disabilities. systems change issues present as a natural outcome of individual complaint resolutions. Last year we represented 792 Kentuckians with 1,317 identified complaints when they entered the system as a P&A client. At case closure, the agency average is 3 complaints per client; 38 percent of our clients have more than one disabling condition.

Because of the complexity of the technical issues related to client complaints, our staffing pattern includes professionals from various disciplines relating to developmental disabilities in addition to our legal staff. It is the philosophy of our agency to resolve clients complaints at the lowest level possible utilizing the court as the last avenue of resolution. We litigate less that 2 percent of our client's complaints. However, we have a deep sense of failure when an unresponsive and often neglectful service system forces us to pursue the lengthy remedy of the court.

Despite the fact that our advocacy staff averaged a 6 day work week last year, we have waiting lists for advocacy services. Our priority system is one that strives to avoid placing a value judgment on who will be harmed more by having to wait for P&A intervention. We believe that advocates do not arbitrarily make these decisions. Because we place a high value on individuals with developmental disabilities, we bear a great burden with the mere knowledge that we cannot meet the demands for advocacy services. We at Kentucky P&A prioritize our services as follows:

1. Emergency (life threatening, denial of food, shelter, medical treatment, or an appeal that has a timeline that must be met)
2. Clients not receiving any services or receiving inappropriate services
3. Clients receiving some services but not all the services they are entitled to.

Currently our largest waiting list is in the area of right to education. At the present time, we are only accepting new cases when the child is out of school, subject to suspension or expulsion, have due process hearing timelines running, or the child appears to be in imminent danger or physical harm in his current placement.

We represent our clients in institutional as well as community related issues. We advocate for the expansion of quality community residential services and in-home support systems. We believe that individuals with developmental disabilities who may reside in the institutional alternative should have had the opportunity to

remain in the community as long as and as independently as they desire rather than being forced into "choosing" the only alternative.

We believe that Kentucky P&A should be a model for other agencies in the area of accountability, client satisfaction, and internal due process procedures. The agency maintains and adheres to comprehensive policy and procedures that fosters consistent and fairly delivered advocacy services. We contract for independent evaluations to review all aspects of our advocacy efforts so that we will be sensitive to areas that may need to be improved and build on identified strengths. We ask each of our clients to evaluate the services they receive and suggest ways we might improve. The client evaluation form is sent when we close our client's case and may be returned unsigned. We feel this encourages our client to freely express any dissatisfaction that they may have about their P&A services.

The Kentucky Protection and Advocacy staff participated in a number of committees, task forces, and boards dealing with issues surrounding early childhood planning, new technologies, and long-term care. The staff was also involved in drafting legislation for special education funding and legislation, which passed, that establishes a right to services for persons with severe developmental disabilities.

Some examples of types of cases handled by Protection and Advocacy in Kentucky are as follows:

1. A local school district placed our client in its home-bound program for 2 hours per week on the grounds that the student was a danger to herself or others. The school then required the student's mother to transport the student to school to receive instruction because the home-bound teacher refused to go to the student's home. The mother was not able to afford the transportation costs in addition to being unaware of her child's right to an appropriate education. Our office was successful in securing an appropriate school based educational program for the student.

2. A teenager with Tourett's Syndrome was denied access to the State's residential Medicaid Waiver Program. The program had been designed for persons with mental retardation and related conditions. Although the young man's IQ scores were marginally high, an appropriate community program requiring the kinds of support which would appropriately serve this individual were available within the Medicaid funded program. After an administrative appeal, P&A was successful in securing the appropriate community residential program for this young man.

3. A 30-year-old Kentuckian was placed in an Intermediate Care facility because he needed an attendant to guide his wheelchair, perform all motor tasks, and interpret his communication which was limited to one or two controlled gestures. He was called too severely disabled for adult activities programs and medically at risk. Repeated encouragement, negotiation, and representation by P&A assisted this young man to secure an integrated community residential placement and a volunteer job. Currently, this individual is employed as a computer operator for a State university in a part-time position making minimum wage.

4. Because she was Medicaid eligible, another Kentuckian was placed in an Intermediate Care facility, i.e., nursing home, despite her age and without regard to her individual needs as a person with mental retardation. Through referral and negotiation, P&A assisted her in getting out of the nursing home and into an age appropriate community setting. She no longer suffers the frequent bruises and abrasions which were caused by having twice the normal clinical level of an anti-convulsive medication in her system.

5. Twenty-two school age children, most of whom were wards of the State, were identified in a nursing home. No one in the group had ever received an appropriate education placement and in our estimation, neither did they receive an active treatment program. These individuals were either placed in cribs or in a bean bag chair 24 hours a day. The day program consisted of a television set being turned on. None of the individuals had been fitted for orthopedic braces, wheelchairs, or any other identifiable assistant devices. I think we would all be appalled at the number of persons who are hidden away in nursing homes such as the one I described.

We have, and continue to receive, reports of individuals who are isolated in attics, basements, a shack out back, and other inhumane modes of hiding family members away from society. As the criminal justice system becomes more sophisticated in recognizing persons with disabilities, we are receiving more and more referrals of individuals in pre and post conviction levels. Most of these individuals have never been in school; many of them are unable to communicate orally, and have little or no understanding about the crime that they have been accused and/or convicted of. In the last few months, a despondent jailor called us to say that he had a young woman in his jail who was beating her head against her cell and was bleeding profusely. He had made numerous attempts to seek some assistance and received none. P&A called the appropriate regional service delivery system, they interviewed the

client and discussed her situation with another service agency that had some responsibility for providing services. Their strategy was to buy the young woman a bus ticket out of town, which they did; they placed her on the bus which she rode to the other side of town and disembark from and was back in jail before the evening sun had set. With great difficulty we were successful in securing the services this young woman desired and needed in the community. Those are but a few of the many types of cases that we work with each year.

Kentucky P&A has been, and continues to be, very active in providing technical assistance and coordination for a State-wide self-advocacy called Kentuckians Together. One of the highlights of the activities in working with self-advocacy is the annual Self-Advocacy Conference. Kentuckians Together elects officers and has a Board of Directors made up of representatives from the community based self-advocacy groups. We provide assistance in coordinating, at their direction, their annual Conference. This 2 day Conference is planned exclusively by consumers themselves with P&A providing assistance in locating Conference speakers and coordinating Conference activities. I could not begin to describe to you the dynamics of approximately 125 adults with developmental disabilities who gather for this Conference to identify State-wide goals for their coming year. Their level of sophistication is astounding when one looks at the number of years these individuals have been isolated in inappropriate residential placement, received little or no services, and continue to confront obstacles that you and I would have most likely caved in to long ago. Persons with developmental disabilities have much that they can teach us if we will only take time to listen. If we accomplish only one thing in Kentucky, it should be that we are responding to the needs ad priorities of the individuals that you have so graciously allowed us to represent.

The Protection and Advocacy System has demonstrated its effectiveness in its first decade of operation, (attached is an appendix of some examples of activities in other States). It is anxious to reach its full potential in its second decade. However, this potential will be achieved only with adequate resources with which to address the needs of all our clients.

APPENDIX A

Examples of the types of client problems and how the Protection and Advocacy system has worked to solve them:

During 1986, the Arizona P&A concluded over 9 years of litigation and received a precedent-setting decision on behalf of a client who was refused employment by the United States Postal Service because of epilepsy. The Agency also successfully represented parents whose child was removed from their care at birth because the mother had a developmental disability and supported a class action case on behalf of Arizonans labelled chronically mentally ill.

PAI of California produced a manual, "Disability Benefits and Work," which dealt with the rights, benefits and responsibilities of Californian's with developmental disabilities who work, or attempt to work under SSDI and SSI program. In addition, self-advocacy materials were distributed in Spanish, Chinese, Vietnamese, Korean, and Cambodian.

The Legal Center in Colorado participated in "Parents Encouraging Parents" weekends sponsored by the Colorado Department of Education, making presentations which included information on the rights of parents and children under P.L. 94-142.

In Florida, the "HAB plan advocacy network" recruits, trains, assigns and supports volunteers who serve as advocates for persons with developmental disabilities who reside in residential facilities and are without family, friends or guardians to advocate for them.

A Personal Care Services medicaid waiver option was implemented in Idaho 4 years ago as a result of litigation instituted by the Idaho P&A and over 400 people who would otherwise have been institutionalized were discharged or "diverted".

In Indiana, the staff and the P&A meets quarterly with the Indiana Department of Education and the Indiana Department of Mental Health to discuss systemic issues. Staff are now involved in reviewing the Indiana Department of Mental Health's draft policies concerning services to persons with developmental disabilities.

Louisiana P&A's *Project Enable* matches senior citizens and people with disabilities with volunteers to assist them with every day tasks. The purpose is to prevent possible institutional placement.

In addition to serving on various committees for other groups and organizations, Nebrasks Advocacy Services (NAS) staff worked with the Nebraska Bar Associa-

tion's Mental Health Law Committee to revise and update its manual on disability law.

During 1986 the New Hampshire Developmental Disabilities Advocacy Center (NHDDAC) doubled the number of individuals it served through training services in the previous fiscal year. A variety of training issues were addressed. Slightly over 10 percent of the people trained were recipients of developmental services, with the remainder being advocates and service providers. In an effort to expand resources, NHDDAC increased its network of private attorneys by trying to increase interest in and knowledge of developmental disabilities.

The North Carolina Protection and Advocacy System sponsored a regional conference on the North Carolina employment discrimination law, and developed and distributed three public service announcements on employment of people with disabilities.

During FY 1986, Oregon Advocacy Center (OAC) initiated a class action suit seeking community services opportunities on behalf of the residents of a training center who have severe to profound mental retardation and who are injurious to themselves and other. OAC also filed a Motion to Intervene in Lawsuit filed by U.S. Department of Justice against the State of Oregon concerning the lack of appropriate treatment, training and education at this training center.

The two law projects under contract with the Pennsylvania Protection and Advocacy (PPA), The Education Law Center, Inc. and the Developmental Disabilities Law Project, initiated eight significant law suits during FY 1986 addressing issues such as enforcing the rights of children with disabilities under Section 504 of the Rehabilitation Act of 1973, meeting the needs of Southeast Asian children in areas such as special education evaluations and programs, school counseling, and bilingual education, and representing the constitutional rights of a woman with mild mental retardation who was illegally and wrongfully institutionalized for almost 30 years without any due process safeguards. In addition, PPA has maintained a monitoring function of State Institutional Facilities for persons who have mental retardation and has been involved in a suit filed against a center by the Public Interest Law Center of Philadelphia.

During FY 1986, South Carolina Protection and Advocacy was involved in filing a 504 complaint on behalf of client of the Department of Mental Retardation alleging discrimination on the basis of their other handicapping conditions. SCP&A also became involved with individuals with handicaps residing in correctional facilities.

Within E.A.C.H., the Tennessee Protection and Advocacy agency, individual case advocacy is provided by volunteers and staff using a team advocacy approach. Volunteers logged over 2,000 hours on cases and training during FY 1986.

The Virginia Protection and Advocacy agency publishes a quarterly newsletter which is distributed to approximately 7,000 people and produced an 8-minute videotape entitled "Know Your Legal Rights" which was distributed to 54 sheltered workshops serving people with developmental disabilities.

Wisconsin Coalition for Advocacy, (WCA) has developed several resources of interest including a report, "Out of Sight, Out of Mind: a Report on the Human and Civil Rights of Residents of Wisconsin's Three State Centers for the Developmentally Disabled," which documents serious patterns of deficiencies and rights violations in Wisconsin's State-run institutions for persons with disabilities.

The Wyoming P&A initiated an appeal on behalf of a woman with a dual diagnosis of mental retardation and mental illness to assist her in retaining her parental rights after signing a consent for Adoption for her 5-year-old son.

The Michigan Advocacy Services forced the closing of a nursing home in which over 100 children with developmental disabilities were inappropriately placed and suffered from abuse, neglect and blatant lack of required educational and health services.

Mr. WAXMAN. Thank you very much.

I understand that each of your organizations is part of the consortium which developed the consensus recommendations for reauthorization of the Development Disability Assistance and Bill of Rights Act. Would each of you very, very briefly indicate to us what you believe are the most important legislative recommendations contained in the consortium document and then tell us if there are any points of disagreement about which the subcommittee should be made aware?

Dr. Guralnick.

M. GURALNICK. Certainly we are most concerned over the years in the DD Act about the total funding for the Act. That is our primary concern. Our secondary concerns are related to the rapidly changing service system and training system that needs to occur in this country and on our personnel concerns of the university affiliated programs we have indicated what our issues are.

We support—in fact since we feel we are truly partners in this entire endeavor we feel that most of the recommendations of the CCDD are in fact compatible and reciprocal with all the other recommendations that have been made by its separate components. There are concerns, I think, the only concern of major disagreement is where in our particular case where the role of the UAF's in paraprofessional training is and there are concerns that need to be worked out there. I think that is a legitimate concern.

Mr. WAXMAN. Dr. Karan.

Mr. KARAN. The American Psychological Association is not a member of the consortium. However, the ASAPA recognizes the increasingly growing needs of concerns related to mental health. Mental health disorders in addition to DD and mental retardation are showing up in profound numbers, returning to institutions or failing in community programs.

Mr. WAXMAN. Yes.

Ms. CUBARNEY. The agencies that I represent do support the consortium. I would just stress that the States would no longer be allowed to ignore that population that does not fit under the mental retardation label and to include those with DD who have normal intelligence but are severely physically impaired.

Mr. WAXMAN. Ms. Peach.

Ms. PEACH. I would like to say that it is the Kentucky experience that persons with DD do not fail in the community but the programs fails them and that we have seen rather than new folks that have begun to show signs of having mental illness, many times our people that have been in a program that has not been designed appropriately and because of the high levels of psychotropic drugs that are often administered through those programs then they do appear to be in fact mentally ill.

We, as I have said earlier, we are opposed to any block grant funding whether we call it generic funding, advocacy is always the first target. I can truthfully say that as Director of the Kentucky Protection and Advocacy Agency that I am the least liked person in the State government. You know, it is the old adage, if you were on fire would they tinkle on you and the answer is, not in Kentucky, and I am not satisfied at the Federal level that we are going to get our share of the funds either.

Mr. WAXMAN. Yes. Thank you very much.

Ms. RAGGIO. We are not well liked in State government either. They refer to us as the skunk at the picnic. I mentioned once or twice in my testimony that we supported various CCDD recommendations and we do. Our priority would be two-fold, the flexibility with the priority areas, and the funding levels.

Mr. WAXMAN. Let me ask whichever of you wishes to comment on it, about the administration's legislative proposal for reauthorization of the DD program. Also you are proposing to significantly

increase the authorization of appropriations for the DD program in fiscal year 1988. Why is this increase necessary?

Ms. CUBARNEY. I would make a comment relative to the population that I represent in that because of the technology explosion and this wonderful bounty that we have had come to us as a result of that, we now have the capability to allow individuals to exercise their intelligence in a meaningful way that was never a possibility before.

But this costs tremendous amounts of dollars at this point. That will decrease over a period of time, but at this point to set people up with the—I can take someone who can only blink their eyes and allow them to access a computer, operate a chair, and control their environment and become employable, become a taxpaying member of this society, but that is only through expensive technology.

Mr. WAXMAN. Dr. Guralnick.

Mr. GURALNICK. In the area of strange, Mr. Waxman, I think in the past few years have really set the stage for crisis proportions in this area. We have had dramatic changes in our system and training needs have not kept pace. Not only have training dollars declined, the fact is, we have tremendous new needs in the area of aging, early intervention, paraprofessional training, and that all suggests that increased appropriations is something that should be supported.

Mr. WAXMAN. Now, does anybody else want to comment on the administration's proposal? I assume you all support the consortiums recommendation for an increase and disagree with the administration's idea, if they could figure it out, what they are recommending as flat funding?

Ms. PEACH. Mr. Waxman, I would like to comment that not only as I alone mentioned, had new technology resulted in increase of demands under the DD Act, but we have a new generation of parents like Eileen that have worked on issues, school issues like P.L. 94-142 and they are finding that after their family members get out of school that the bottom drops out. It just isn't there.

Also, I think through protection and advocacy I know that as a national system we are identifying daily people we would hope would be 6 years old and are just finding out they have some rights to some services, but we are running into a lot of people that are 30 years old, you know, and the response has been, "My gosh, everybody just said no."

So there is more of an awareness. This population that has been voiceless so to speak is restless and you are going to be hearing more and more from them demanding their piece of the American dream.

Mr. WAXMAN. Do any of you wish to comment on the idea of data collection? Do you think we have adequate Federal data collection programs now and are they adequate? Should the Government be doing more?

Ms. PEACH. As a national P&A system, we feel that data collection is very important, especially when we come before committees in order to justify our very existence. We feel there is not enough data collected State and Nationally in order for us to adequately do the planning that we say we are doing and addressing some of the systems issues that we need to address.

So we find it important, and we find it important enough that we don't want to wait for those—what is that terminology, adequate funds as may be necessary. We would like to see that money set aside for that very purpose.

Mr. WAXMAN. Just as a clarification, when they ask for such funds as may be necessary, that doesn't set an authorization amount, but allows the appropriations committee to go to any amount it chooses. They can go higher than what the consortium is recommending. They can appropriate the administration's level or the consortium's level or choose another number.

So when the administration asks us to say the authorization level is such sums as may be necessary, that shifts the issue over to the appropriations committee for them to study in order to decide on the actual amount. That is why I was questioning very carefully what they were going to ask the appropriations committee for because if they were not going to ask for adequate funding, we would like to know about it and play a role in influencing the appropriations committee's deliberation.

Mr. Sikorski.

Mr. SIKORSKI. No, thank you, Mr. Chairman.

Mr. WAXMAN. You have done an excellent job.

I want to thank each of you for your testimony.

We look forward to working with you on this legislation. That concludes our hearing for this morning. We stand adjourned.

[Whereupon, at 11:05 p.m. the hearing was adjourned.]

[The following statement was submitted for the record:]

AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION BY ROGER P. KINGSLEY, DIRECTOR, CONGRESSIONAL RELATIONS DIVISION, GOVERNMENTAL AFFAIRS DEPARTMENT

As the professional and scientific association representing 52,000 speech-language pathologists and audiologists nationwide, the American Speech-Language-Hearing Association (ASHA) is very concerned about the adequacy of services to infants and young children with disabilities. We are pleased that, as part of the reauthorization of the developmental Disabilities Act, the subcommittee is examining the problems of adequate health care, rehabilitation, and special education and related services among infants and young children with serious disabilities. As a result of the new mandate in P.L. 99-457 to serve children 5 years and under, the issue of adequate numbers of qualified personnel must be addressed.

PROVISIONS IN THE LAWS FOR SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY SERVICES

Both the Developmental Disabilities Act and the Education of the Handicapped Act contain provisions for the training of personnel to serve individuals with disabilities.

Among the purposes of the Developmental Disabilities Act (Part A, 101 (c) and (d)) is

> ". . . to train professional and paraprofessional personnel with respect to providing services to persons with developmental disabilities;" and "to make grants to university affiliated facilities to assist them in administering and operating demonstration facilities for the provision of services to persons with developmental disabilities and interdisciplinary training programs for personnel needed to provide specialized services for these persons."

The DD Act also provides for service activities (Section 102(11)(B)) for

> "the training of personnel, including parents of persons with developmental disabilities, professionals, and volunteers, to provide services . . ."

University affiliated facilities are public or nonprofit facilities which are associated with colleges or universities and which provide for activities including (Section 102(13)(A))

"Interdisciplinary training for personnel concerned with developmental disabilities which is conducted at the facility and through outreach activities."

Both laws recognize the prevalence of children with speech, language, and hearing disorders and the need to provide services to this population. The definition of developmental disabilities (Part A, Section 102(7)(D)) refers in part to

"substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction (vi) capacity for independent living, and (vii) economic self sufficiency."

Clearly, a major purpose of the Developmental Disabilities Act is to provide services to people with disabilities, including disorders of communication, by appropriately trained personnel. Last year, Congress addressed the "urgent and substantial need" for early intervention services to children ages birth through two who have or are at the risk of developing (at the State's discretion) disabilities. The purposes of the new program are:

"(1) to enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay, (2) to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after handicapped infants and toddlers reach school age, (3) to minimize the likelihood of institutionalization of handicapped individuals and maximize the potential for their independent living in society, and (4) to enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps."

The Education of the Handicapped Act Amendments of 1986 (P.L. 99-457) includes in the definitions of "handicapped infants and toddlers" and "early in "(i) physical development, (ii) cognitive development, (iii) language and speech development, (iv) psycho-social development . . ." all of which relate to communication disorders. Among the specific services that must be provided under Section 672(2)(E) are "(iii) speech pathology and audiology." And, these services are (F) [to be] "provided by qualified personnel, including—(i) special educators, (ii) speech and language pathologists and audiologists . . ." P.L. 99-457 also includes a provision for Part H (Section 676(b)(14)) and an amendment to Part B—Basic State Grants for the Education of All Handicapped Children—(Section 613(a)(13)) which requires that States ensure that personnel meet the highest standard for qualification to practice in a particular professional discipline. The purpose of this amendment was to require States that permit the use of emergency or temporary credentials or that allow a lesser professional standard for school-based personnel to reform these practices in a manner that will guarantee that children with disabilities receive the same quality services available to people under other public programs.

COMMUNICATION DISORDERS IN THE EARLY CHILDHOOD POPULATION

The Department of Education reported that during the 1984-85 school year there were 4,363,031 handicapped children served under P.L. 94-142 and 89-313.[1] During this same period there were 259,483 preschool-age children served.[2] While a majority of children in the 3 through 5 age group are presently receiving special education and related services, P.L. 99-457 expands the Preschool Grant Program so that by the early 1990's, all preschool-age children with disabilities will be served.

Children with speech or language impairments represent the second largest category of handicapped children, with 1,129,417 children served during the 1984-85 school year:[3] The Department of Education reports that while the number of speech or language impaired children in the 6-21 age range is declining, there has been a concurrent increase in the number of 3-5 year olds with such disorders. With the preschool population growing at a faster rate than the general school-age population, the Department predicts an increase in the number of young children with communication disorders in the coming years.[4]

The vast majority of preschool-age children served (70.5 percent) had a primary handicap of speech or language impairment.[5] This does not include the large

[1] U.S. Department of Education, Office of Special Education Programs, *Eighth Annual Report to Congress on the Implementation of the Education of the Handicapped Act* (1966), p. 1.
[2] U.S. Dept. of Ed., p. 9.
[3] U.S. Dept. of Ed., p. 8.
[4] U.S. Dept. of Ed., p. 8.
[5] U.S. Dept of Ed., p. 16.

number of children with other primary handicaps (e.g., mental retardation, cerebral palsy, learning disability, hearing impairment, multiple handicaps) who have concomitant speech or language disorders.

Because services to children with disabilities below the age of 3 have been available in some States and in some programs but notothers, few data exist on the overall prevalence of children served and unserved in this age group. We do know, however, that there is a substantial need for services to children ages birth through 5 who have communication disorders. A 1986 ASHA survey found that children ages 0–5, inclusive, comprised 26.8 percent of the caseloads of speech-language pathologists and 25.1 percent of the caseloads of audiologists.[6]

As more is learned about the causes of serious physical and mental disabilities, strategies can be developed for reducing the incidence of such disabilities in newborns. However, this Nation has only begun to deal with problems like congenital defects and low birth weight that are often the cause of mental retardation, autism, deafness, cleft palate and other conditions with associated speech, language and hearing disorders. At the same time as progress is made in alleviating disease and disability in some areas (for instance through family planning, accident prevention, and infant screening), new problems arise in other areas (like infants born with diseases and disabilities resulting from maternal use of drugs and/or alcohol and AIDS). Between 100,000 and 150,000 children with congenital anomalies which result in mental retardation are born each year (3–5 percent of all newborns). Many of these children have additional disabilities and another 1–2 percent of infants are born annually with just physical disabilities.[7] A 1983 study found that a significant number of infants, toddlers and preschoolers were hospitalized primarily as a result of a disease of the nervous system and sense organs (including communication disorders)—16.7 per 1,000 children under 1 year old and 9.7 per 1,000 children ages 1 to 4.[8] Included in the list of most common diagnoses in the Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program are hearing impairments in young children.[9]

EARLY INTERVENTION PERSONNEL NEEDS

With a high prevalence of very young children with disabilities, including disorders of speech, language and hearing, and a broad new national mandate for serving these children, it is imperative that adequate numbers of qualified personnel are trained and available to provide necessary services. The Department of Education reports that the number of special education teachers has risen annually since the implementation of P.L. 94–142 began in 1976. However, the Department also found that 17,103 additional special education teachers were needed and that there were particular shortages of personnel in several areas including multihandicapped, hard-of-hearing and deaf.[10] The personnel problem is more serious than the figures indicate because they do not take into account the number of special education personnel who are unqualified or underqualified to serve children with particular kinds of disabilities.

The authors of a major study of special education personnel stated that

> "When supplies of any resource are plentiful, the tendency is to sort and select the superior; when supplies are scant, one settles for less. In special education, the most widespread solution to problems of personnel shortages and recruitment problems is the issuance of certificates to persons who do not demonstrate the preparation, experience, qualifications, and other criteria ordinarily used for certification . . . "These same (certification) policies also make it possible for districts to increase the supply of personnel by assigning to special education those individuals who are neither prepared, qualified, nor certified to work with handicapped students." [11]

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[6] American Speech-Language-Hearing Association, Omnibus survey (1986).

[7] U.S. Department of Health and Human Services, Report to the President. *Mental Retardation: Prevention Strategies that Work* (1980), p. 3. (Because of differing definitions and reporting methods, no firm figure can be given, so a range is used).

[8] McCarty, E. and Kozak, L.J., "Hospital Use by Children: United States, 1983." *Advance Data*, National Center for health Statistics (1985), No. 109. Data from the 1983 National Hospital Discharge Survey.

[9] Health Care Financing Administration, *Early and Periodic Screening, Diagnosis, and Treatment*, EPSDT Program Report (1984).

[10] U.S. Dept. of Ed., *Eighth Annual Report*, p. 68.

[11] Smith-Davis, J., Burke, P., Noel, M.—Institute for the Study of Exceptional Children and Youth, *Personnel to Educate the Handicapped in America: Supply and Demand From a programmatic Viewpoint* (1984), p. 229–30.

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The study also reported that

> Undersupplies of personnel in speech/language/communication . . . present themselves a serious national needs." [12]

RECOMMENDATION

Speech-language pathologists and audiologists are qualified by their education and training to serve young children with communication disorders. These qualifications include a master's degree and a year of supervised clinical experience. Much of the clinical practicum is in university speech-language-hearing clinics and is with infants and preschoolers because these are the groups that have not previously been served in the schools in many States. Hence, the ability of speech-language pathologists to provide services to the 0–5 population is demonstrated by the academic training and clinical experience of persons who hold national certification and/or State licensure.

Although the vast majority of certified speech-language pathologists and audiologists provide services exclusively to children or work with children and adults, only 2 percent provide services to children in the 0–2 age range and 15 percent serve children ages 3–5.[13] In order for the States to meet the early intervention needs of children, more support for personnel training is needed. ASHA supports the initiative of the American Association of University Affiliated Programs (AAUAP) in recommending $1 million to provide support for the development and implementation of training projects in university affiliated facilities under the Developmental Disabilities Act. These projects would be targeted at interdisciplinary training of personnel to provide early intervention services. Although the bulk of personnel preparation will continue to be supported through Part D of the Education of the Handicapped Act, we believe that existing authorization levels cannot adequately meet the service and personnel needs that presently exist and that will grow as States plan and implement services to the 0–5 population. We suggest that additional training must take into account the new mandate for qualified professionals and that it must address areas of particular need with respect to the current lack of qualified providers of special education, health and related services.

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[12] Smith-Davis et al., p. 52.
[13] ASHA, Omnibus Survey (1986).

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